

STATE OF VERMONT NEEDS ASSESSMENT OF INDIVIDUALS WITH TRAUMATIC BRAIN INJURY AND THEIR FAMILIES

Presented to:

**The Traumatic Brain Injury Program
Division of Vocational Rehabilitation
Vermont Department of Aging and Disabilities
Agency of Human Services**

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Needs Assessment of Individuals with Traumatic Brain Injury and Their Families

Executive Summary

August 6, 2003

In 2001, Vermont was awarded a Traumatic Brain Injury (TBI) Planning Grant from the Federal Health Resources and Services Administration, Maternal and Child Health Bureau, to conduct an assessment of the needs of individuals with TBI and their families and to develop a plan for a comprehensive statewide system of services to address those needs. The lead agency for the planning grant is the Traumatic Brain Injury Program (TBI Program), located in the Division of Vocational Rehabilitation of the Department of Aging and Disabilities. The needs assessment was carried out with the assistance of Flint Springs Consulting. Needs assessment activities took place over a thirteen-month period from July 2002 through July 2003.

The needs assessment was designed to gather information in five key areas of focus:

1. How prevalent is TBI in Vermont?
2. How do individuals with TBI get into the system of support services?
3. What do individuals with TBI and their families need?
4. What barriers prevent individuals with TBI and their families from using existing services?
5. How do we know if the service system is meeting the needs of individuals with TBI and their families?

The needs assessment employed three complementary data collection strategies to gather information about a variety of questions in each area of focus. Surveys of individuals with TBI and providers were conducted to collect quantitative data. Two methods were utilized to gather qualitative data: focus groups were held with 16 individuals with TBI/family members, and individual key informant interviews were conducted with 24 professionals and advocates.

Separate survey tools were developed for individuals with TBI and service providers. In total, 2,544 surveys were distributed to individuals with TBI and service providers, with an overall response rate of 14.7% (373 surveys). Of the 1,419 surveys distributed to individuals with TBI, 190 completed surveys were returned (13.4%). Of the 1,125 surveys distributed to providers, 183 completed surveys were returned (16.3%).

Incidence and Prevalence. In Vermont, as in most other states, it is challenging to determine the exact incidence and prevalence of brain injuries. Available data on brain injuries is limited to hospital inpatient and outpatient discharges. These counts of moderate to severe injuries may be duplicative and data sources for mild to moderate injuries are lacking. The needs and resources assessment recognizes that Vermont must improve and expand its systems to track the incidence and prevalence of TBI in Vermont, particularly for mild to moderate TBI.

The annual average number of discharges following hospitalization for traumatic brain injury in Vermont is 375 (1997-2001). When inpatient discharges for arteriovenous malformation (AVM) are included, the average annual number of TBI inpatient discharges increases to 388. For the year 2001, there were a total of 105 TBI ambulatory discharges, i.e. outpatient surgical procedures. Over all age groups, the incidence of TBI was higher for males than for females. With the exception of inpatient hospital discharges for males age 70 and above, incidence of TBI is highest for males between the ages of 15 and 24.

Referral to the System of Services and Supports. A recurring theme was that individuals with severe brain injury are more likely to be referred to and receive TBI services than those with mild and moderate injuries. Individuals with TBI, both children and adults, access or are referred to services and supports through a wide variety of educational, vocational, medical and social service providers. There is no overall system to connect individuals with TBI and their families to services and supports. The only nexus for TBI services that emerged was the TBI Waiver Program, which serves only individuals with moderate to severe TBI.

Service and Support Needs. Information drawn from all three information sources – the focus groups, key informant interviews, and surveys – pointed to the following as the most important elements in a system of services for individuals with TBI and their families:

- Employment, including long-term employment supports (work was reported by individuals with TBI as the area of life changed most by TBI)
- Family supports and respite
- Home-based services (life skills aides, personal care attendants, home health aides, nursing care)
- Information and referral (accurate, consistent information to assist with accessing appropriate services)
- Case management or service coordination (consistent, ongoing case management across service providers and treatment settings)

- TBI Waiver or Waiver-type services (including case management, funds for TBI services, and supports)
- Trained and knowledgeable health care, mental health, and direct care providers
- Long-term services and supports (including rehabilitation therapies, case management and home-based services without durational limits, and ongoing employment supports)
- Transportation

Additional elements identified by the needs assessment as important to a system of services for individuals with TBI and their families are:

- Flexible systems and funding (including eligibility barriers and insurance limits)
- Financial assistance for daily living and services
- Social opportunities, support groups, and counseling
- Public education and awareness, including prevention
- Rehabilitation therapies

Barriers to Services. Barriers to services and supports mirror the needs and gaps in the service system identified by the needs and resource assessment. They include:

- Lack of knowledge about TBI among providers, as well as individuals with TBI and their families
- Lack of information or inaccurate information about TBI services
- Ineligibility for services and financial support due to age, severity of injury, pre-existing injury, and/or income
- Lack of funding and services for long-term support (home and community based and employment)

Outcomes of a Successful System of Services and Supports. The primary measure of success in meeting the needs of individuals with TBI and their families was identified in various ways as satisfaction with quality of life. Quality of life includes:

- Meaningful occupation or daily activities

- Successful employment
- Successful transition from school to adult life
- Social opportunities and community participation
- Time and opportunities for enjoyment, laughter, and fun
- Community integration
- Progress in recovery

Conclusion. Vermont currently does not have a comprehensive system of services for individuals with TBI and their families. In general, the more severe the injury and the higher the level of need, the more likely an individual with TBI is to receive comprehensive services and supports. In particular, the system lacks services for people who have suffered mild to moderate TBI. This is closely tied to the fact that these individuals frequently are unidentified. Lack of identification in turn is tied to lack of awareness about TBI among the general public, professionals, educators and service providers. Inadequate data sources to track incidence and prevalence of mild to moderate TBI also contributes to this problem.

For individuals with TBI who meet its eligibility criteria, the services provided under the TBI Waiver are regarded as comprehensive, appropriate, and of high quality. But even the TBI Waiver is not designed to meet the long-term needs of many individuals with TBI and their families. For individuals with TBI who are not Waiver-eligible, it is difficult to access comprehensive services, even for those with private insurance coverage or personal financial resources. For these individuals, it is a patchwork of services and supports with gaps and varying eligibility requirements.

Vermont has a number of model programs to address the needs of individuals with TBI and their families. However, information gathered from all sources in the needs and resource assessment, as well as from TBI Program staff, points to the need to create a comprehensive system of TBI services and supports for Vermonters with TBI and their families.

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I. Introduction

In 2001, Vermont was awarded a Traumatic Brain Injury (TBI) Planning Grant from the federal Health Resources and Services Administration, Maternal and Child Health Bureau, to conduct an assessment of the needs of individuals with TBI and their families and to develop a plan for a comprehensive statewide system of services to address those needs. The lead agency for the planning grant is the Traumatic Brain Injury Program (TBI Program), located in the Division of Vocational Rehabilitation of the Department of Aging and Disabilities. The needs assessment was carried out with the assistance of Flint Springs Consulting.

Input from a broad-based Advisory Board, composed of individuals with TBI, family members, advocates, and representatives of state agencies and providers, has been integral to all phases of the needs assessment process and will continue during the planning phase of the grant. A Steering Committee, drawn from the Advisory Board, worked closely with staff from the TBI Program and the consulting team during the implementation of the needs assessment.

II. Overview of Traumatic Brain Injury

Traumatic Brain Injury and Its Effects

Brain injury is an insult to the brain, not of degenerative or congenital nature, the result of either an external physical force or internal cause, that produces an altered mental status, which results in an impairment of behavioral, cognitive, emotional, and/or physical functioning.¹ Nationally, the leading causes of traumatic brain injury (TBI) include vehicle accidents, falls, firearms and other violence.²

TBI may affect speech, vision, hearing, touch, smell, and taste, and cause lack of fine motor coordination, spasticity, paralysis, headaches and seizures. Cognitive effects often include short and long-term memory deficits, slowed thinking, limited attention span, and impairments in perception, concentration, communication, reading, writing, planning, sequencing, and judgment. Behavioral and emotional disabilities may include fatigue, mood swings, denial, anxiety, depression, lowered self-esteem, sexual dysfunction, restlessness, and lack of motivation. Individuals with TBI may also experience difficulty with emotional control, ability to cope, agitation, and relating to others.

¹ Vermont Division of Vocational Rehabilitation, 1999

² National Center for Health Statistics, Centers for Disease Control

The Consequences of Brain Injuries³

Cognitive Consequences Can Include:

- Short-term memory loss; long-term memory loss
- Slowed ability to process information
- Trouble concentrating or paying attention for periods of time
- Difficulty keeping up with a conversation; other communication problems such as word-finding
- Spatial disorientation
- Organizational problems and impaired judgment
- Inability to do more than one thing at a time
- Lack of initiating activities, or once started, difficulty in completing tasks without reminders

Physical Consequences Can Include:

- Seizures of all types
- Muscle spasticity
- Double vision or low vision, even blindness
- Loss of smell or taste
- Slowed or slurred speech
- Headaches or migraines
- Fatigue; increased need for sleep
- Balance problems

Emotional Consequences Can Include:

- Increased anxiety, depression, and mood swings
- Impulsive behavior; easily agitated
- Egocentric behaviors; difficulty seeing how behaviors affect others

In comparison with other types of injuries, brain injuries are among the most likely to lead to permanent disability or death.⁴ Advances in medicine and technology mean that today many more people survive a traumatic brain injury. But many of these individuals with TBI face lifelong physical, cognitive, emotional and behavioral challenges that may require long-term services and supports.

³ National Center for Injury Prevention and Control, Centers for Disease Control

⁴ National Center for Injury Prevention and Control, *Traumatic Brain Injury*,
www.cdc.gov/ncipc/factsheets/tbi.htm.

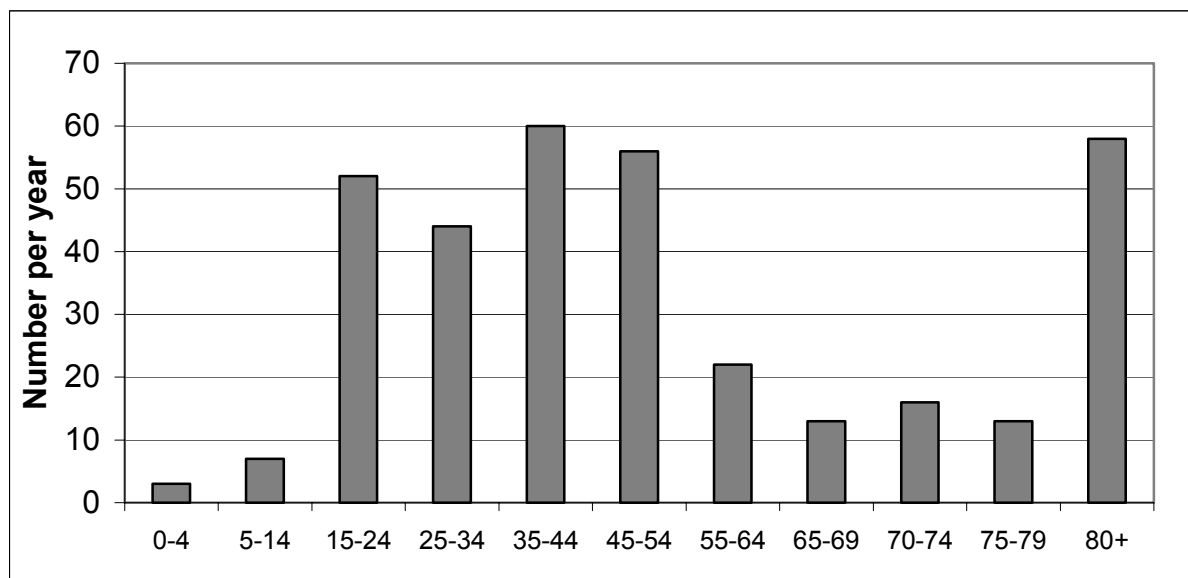
Incidence and Prevalence of TBI

Note. Data provided on the incidence and prevalence of TBI must be viewed with caution. Both nationally and in Vermont, the sources of the data are primarily mortality and hospital visits. Because of these sources, it is generally acknowledged that the data primarily reflect incidence of moderate to severe TBI, but probably do not include many of the people with mild to moderate brain injuries who are not seen in a hospital and/or whose brain injuries may go undiagnosed. In Vermont, there are no unique personal identifiers attached to hospital data. This means that hospital data may reflect multiple admissions and/or outpatient procedures on the same individual.

In the United States, it is estimated that 1.5 million people sustain a brain injury annually. For 80,000 of these individuals with TBI, the brain injury marks the onset of long-term disabilities.⁵ The following sources of data will be examined for TBI incidence in Vermont: deaths, inpatient hospital discharges, and ambulatory surgery discharges.

In Vermont, for the period from 1997- 2001, TBI was a contributing (as opposed to underlying) cause of death in 344 cases – 259 males and 85 females. Figure 1 reflects that, excluding the elderly population, TBI was most often a contributing cause of death for males between the ages of 15 and 54.⁶

Figure 1: TBI Related Deaths by Age Group Vermont 1997-2001

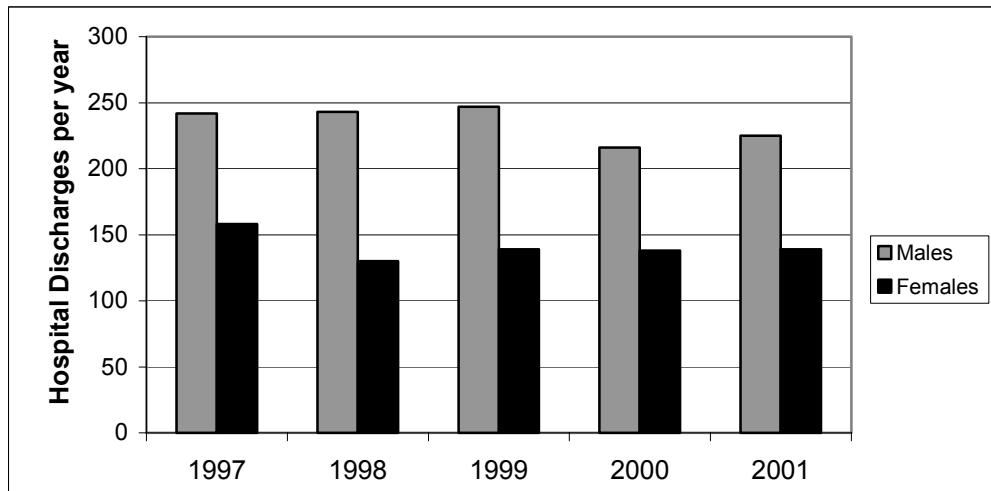


Vermont hospital data for the years 1997-2001 indicate a total of 1,877 discharges following hospitalization for traumatic brain injury (Figure 2), or an average of 375 discharges per year.

⁵ National Center for Disease, *Traumatic Brain Injury in the United States: A Report to Congress* (January 16, 2001), www.cdc.gov/ncipc/pub-res/tbicongress.htm.

⁶ All Vermont data was provided by the Vermont Department of Health. Thanks to Caroline Dawson, Public Health Analyst, Division of Health Surveillance, for her assistance.

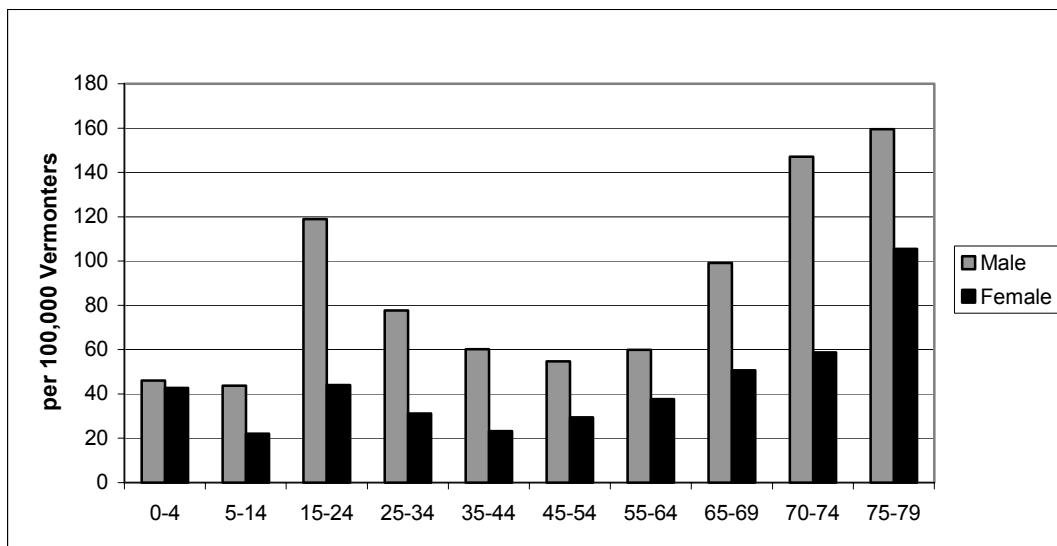
Figure 2: Traumatic Brain Injury Hospitalizations 1997-2001



Source: Vermont Hospital Discharge Dataset
ICD-9-CM Code 800.0-801.9, 803.0-804.9, 850.0-854.1, 959.01

As shown in Figure 3, Vermont rates of hospitalization for TBI are consistently much higher for males than for females, with the highest rates for males between the ages of 15 and 24 and agz 70 and above.

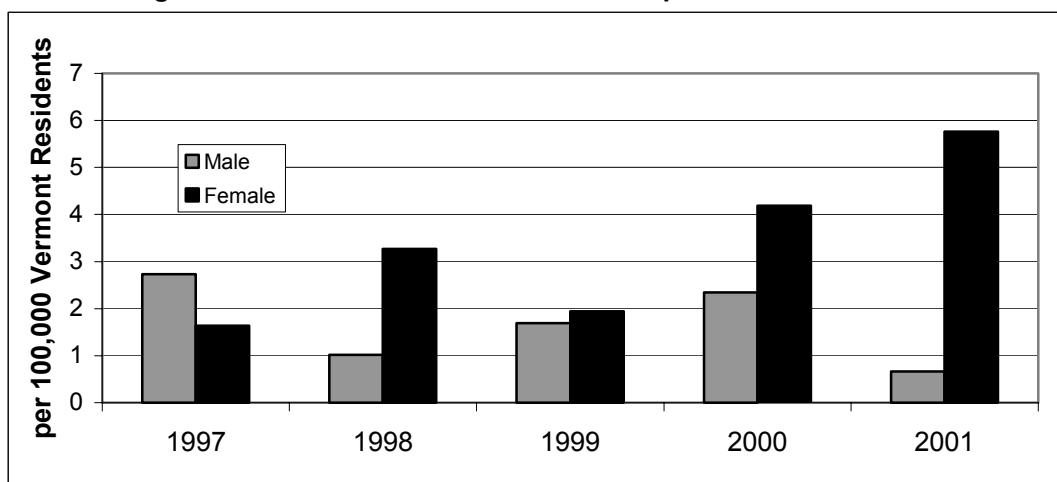
Figure 3: Traumatic Brain Injury Hospitalizations by Age Group 1997-2001



Source: Vermont Hospital Discharge Dataset
ICD-9-CM Code 800.0-801.9, 803.0-804.9, 850.0-854.1, 959.01

The TBI Program and TBI Waiver also serve young adults who have suffered a TBI as the result of an arteriovenous malformation (AVM). Though the numbers are relatively small – a total of 67 individuals under age 55 for the years 1997-2001—this population should be taken into consideration when Vermont assesses its needs for TBI services and supports. (Figure 4.)

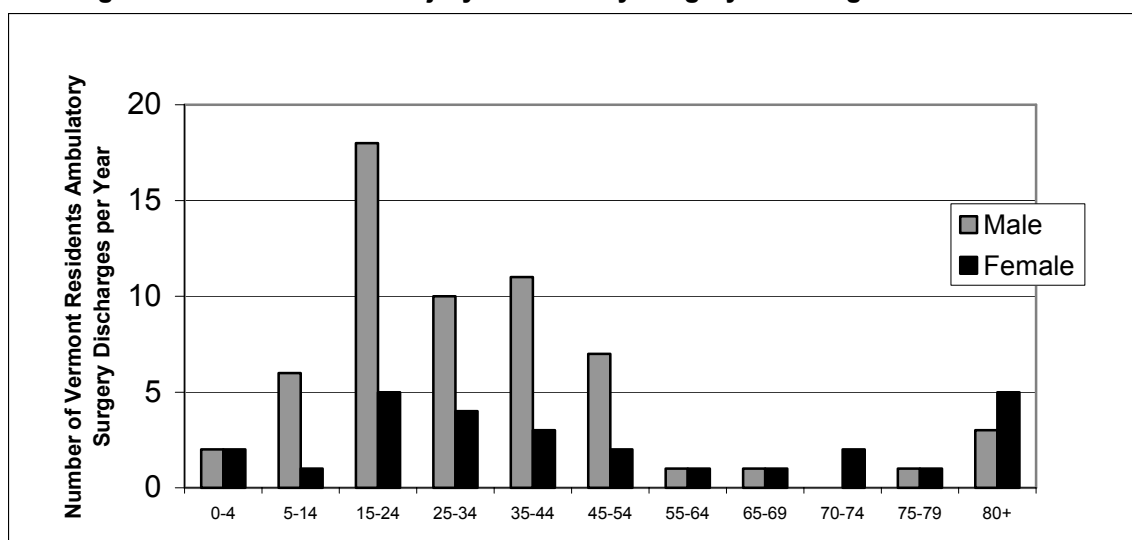
Figure 4: Arteriovenous Malformation Hospitalizations 1997-2001



Source: Vermont Hospital Discharge Dataset
ICD-9-CM Code 747.81

In 2001, the definition of ambulatory surgery was expanded to include all outpatient surgical procedures.⁷ For the year 2001, there were a total of 105 TBI ambulatory discharges. Again, the highest numbers were for males between the ages 15 and 24. (Figure 5)

Figure 5: Traumatic Brain Injury Ambulatory Surgery Discharges Vermont 2001



Source: Vermont Hospital Discharge Dataset
ICD-9-CM Code 800.0-801.9, 803.0-804.9, 850.0-854.1, 959.01

Though Vermont now collects information on TBI treated in emergency departments, those data are not yet available. However, in the future those data may be a valuable source of information on incidence and prevalence of TBI, including mild to moderate injuries.

⁷ Previously, the ambulatory surgery included only outpatient procedures done in an operating room.

III. Overview of Current TBI Services in Vermont

Prior to implementation of the formal needs assessment methodologies, the consulting team interviewed the staff of the TBI Program to obtain their perspective on current services for individuals with TBI and their families, as well as their assessment of unmet needs. This overview summarizes information gathered through interviews with the TBI Program Coordinator and a TBI Program Specialist, as well as other information provided by them.

Comprehensive System of Services for TBI

Currently, Vermont does not have a comprehensive system of services for individuals with TBI. With the exception of those individuals who are eligible for the Home and Community Based Medicaid Waiver for Individuals with TBI (TBI Waiver), Vermont has a patchwork of services and supports that does not address the comprehensive needs of children, youth, adults, and elders with TBI. Availability of services depends on a multitude of factors such as eligibility for Medicaid or Medicare, severity of injury, length of time since injury, age, range and duration of coverage under private insurance or Workers Compensation, and geographic location. In general, individuals with greater severity of injury and higher degree of need receive better services and supports.

The critical gaps in the Vermont's services identified by TBI Program staff, based on their knowledge and experience, were highly consistent with the findings of the needs assessment.

Agencies and Organizations Providing Specialized TBI Services

TBI Program. The TBI Program is the focal point of services for individuals with TBI in Vermont. In addition to administering the statewide TBI Waiver, it provides training and consultation on TBI, fosters collaboration and coordination of TBI services, and supports new TBI initiatives. The TBI program is staffed by a program coordinator and two program specialists with expertise in employment and mental health issues for individuals with TBI, respectively.

- **TBI Waiver:** The TBI Waiver serves approximately 50 individuals with TBI annually. The goal of the Waiver is to support individuals with TBI to obtain their optimum level of independence in their communities. Services and supports available through the TBI Waiver include: case management; one-to-one rehabilitation supports; twenty-four hour supervision; assistive technology; respite services; crisis supports; psychological and counseling supports; and employment services. Services are provided through 19 local organizations that have been approved as TBI Waiver providers. To be eligible for the Waiver, an individual with TBI must be: age sixteen or older;

eligible for Medicaid; diagnosed with a recent moderate to severe brain injury; require one-to-one instruction focusing on independent living; demonstrate the ability to benefit from rehabilitation; and demonstrate potential for living independently and returning to vocational activities. Though originally designed to provide short-term services and supports (up to two years), the Waiver now includes a long-term option for people who require ongoing intensive one-to-one community based supports. However, this long-term option is limited by State and Federal Medicaid dollars. Therefore, it is only available to a select number of individuals with TBI, most of whom also carry a diagnosis of mental illness and have a history of institutionalization.

- **Consultation and Training:** The TBI Program provides one-to-one consultation to individuals with TBI and their families. For individuals with TBI who are ineligible for the Waiver, the TBI Program provides information and referral services to other resources. Consultation and training are also provided to professionals, service providers, schools, and other state agencies. The Annual Vermont TBI Conference, now co-sponsored with the Brain Injury Association of Vermont (BIA-VT), provides additional training opportunities for individuals with TBI, families, professionals, service providers and advocates.
- **Coordination and Collaboration:** The TBI Program collaborates with other service providers, advocacy organizations, and state agencies to develop new initiatives to support individuals with TBI and to encourage coordination of services. Examples of such initiatives include: supported employment options that coordinate the resources of DVR, the Head Injury Stroke Independence Project, and the Professional Nurses Service; a supervised apartment project in collaboration with the Head Injury Stroke Independence Project; long-term one-to-one intensive community supports in collaboration with DVR and the Division of Mental Health Services; specialized TBI employment consultation in coordination with DVR and UVM; and a guide to program development for children and adolescents with TBI published in collaboration with the Department of Education and the University of Vermont.

Brain Injury Association of Vermont (BIA-VT). BIA-VT provides support to individuals with TBI, their families, professionals, and services providers through statewide education and training, individual and systems advocacy, information and referral, and support groups. The organization works closely with the TBI Program, including co-sponsorship of the Annual TBI Conference.

Head Injury Stroke (HIS) Independence Project (Lenny Burke Farm). The HIS Independence Project provides education, services, and support to people with head injury/stroke and their families. Services include information and referral, support groups, and, in collaboration with the TBI Program, supported living and supported employment initiatives.

TBI Specific Residential and Independent Living Services. Five organizations in Vermont – Lenny Burke Farm, Riverview Life Skills Center, S.U.C.C.E.S.S., Williams House and Eagle Eye Farm, Inc. – provide a variety of services in programs designed specifically for individuals with TBI. Services include: residential treatment; supported residential services; case management; life skills development; psychotherapy and counseling; behavior management; cognitive rehabilitation; employment; social and recreational activities; support groups; crisis support; respite and family support.

Hospitals. Three major hospitals serving Vermont – Fletcher Allen Health Care, Rutland Regional Medical Center, and Dartmouth Hitchcock Medical Center (in coordination with Mt. Ascutney Hospital) – provide acute rehabilitation services to individuals with TBI. The quality of case management, family education, and discharge planning varies among facilities. All Vermont hospitals provide sub-acute outpatient rehabilitation services if prescribed by a physician; the length of these services is dependent on the individual's insurance coverage.

Non-Specialized Agencies and Organizations Providing Services

A number of other state and local public agencies and private non-profit organizations provide community based services and support for individuals with TBI and their families. Access to services depends on eligibility for specific programs and is frequently limited by availability of funds or staff resources. The appropriateness of these services varies depending on the needs of the individual with TBI and the specialized training of the provider. Key non-specialized providers include:

Division of Vocational Rehabilitation (DVR). In addition to vocational rehabilitation services available to people with all disabilities, DVR has a set-aside fund designated for assessment of the employment needs and case management for individuals with TBI. DVR also contracts with Lenny Burke Farm to provide a supervised apartment program. Limitations on the length of time that DVR can serve an individual means that vocational rehabilitation services do not fully address the long-term employment supports required by many individuals with TBI.

Division of Developmental Services (DDS). People with developmental disabilities who also have TBI or whose TBI resulted in a developmental disability prior to age 22 may be eligible for Developmental Disabilities Waiver services, such as housing, community and employment supports, case management, and respite.

Division of Mental Health (DMH). Individuals with TBI who carry a dual diagnosis of mental illness may be eligible for mental health services delivered through community mental health agencies. Two of Vermont's local community mental health agencies are also approved TBI providers.

Department of Education and Local Educational Agencies. A TBI specialist in the Department of Education provides one-on-one consultation to families and local school teams delivering educational services to children with TBI. Children and youth with TBI

may receive special education and related services under an Individualized Education Program or accommodations under a Section 504 plan. Children up to age 3 may receive case management, educational, and rehabilitation services through the Family, Infant and Toddler Program, co-led by the Agency of Human Services and the Department of Education. Under-identification and misdiagnosis of children and youth with TBI, as well as lack of specialized TBI training for educators, are thought to result in lack of appropriate services and accommodations.

Department of Health. Children with Special Health Needs provides medical and social work services, including case management and service coordination, to children and youth with a variety of severe disabilities, including TBI.

High Tech Program. Located in the Office of Vermont Health Access (Medicaid), the High Tech Program coordinates Medicaid-funded assistive technology and home health services to enable children with severe disabilities, including TBI, to be cared for at home rather than in a hospital, out-of-state skilled nursing or acute rehabilitation facilities.

Department of Aging and Disabilities (DAD). In addition to being home to DVR and the DVR TBI Program, DAD oversees a number of other programs for elders and adults with disabilities. These include the Home and Community Based Waiver for the Aging and Disabled, the Enhanced Residential Care Waiver, and programs that provide personal attendant care, homemaker services, and adult day services. The activities provided and the skill level of staff are not always appropriate to the needs of individuals with TBI.

Home Health Agencies/Professional Nurses Services. Vermont's non-profit home health agencies and Professional Nurses Services provide services to individuals with TBI funded through the TBI Waiver, other waiver programs, Medicare, private insurance, and private payment. Depending on the parameters of the funding source and the staff expertise, home health agencies provide case management, direct care, supported employment counseling, life skills aides, mental health services, and rehabilitation therapies.

Vermont Center for Independent Living (VCIL). VCIL has a variety of services that support independent living for people with disabilities, including individuals with TBI. Programs used by individuals with TBI include the peer counseling program and the home access program, which assists with home modifications.

Vermont Protection and Advocacy (VTPA). Under a recent grant from the Federal Health Resources and Services Administration, Maternal and Child Health Bureau, VTPA is now engaged in individual and systems advocacy and training activities focusing on TBI. In coordination with the Disability Law Project of Vermont Legal Aid (DLP), it provides advocacy for individuals with TBI currently living in institutional settings to help them gain access to community based services and supports. In collaboration with partner organizations, it advocates at the systems level for enhancements and coordination of TBI services and supports. Together with BIA-VT and DLP, VTPA provides training to individuals with TBI and their families, service

providers, and professionals on rights (e.g., patient rights, ADA) and entitlements (e.g. special education, Medicaid/Medicare, SSI) for individuals with TBI.

Nursing Homes. Nursing homes in Vermont provide short-term inpatient rehabilitation therapy, as well as long-term care for a very small number of younger adults with TBI. However, most of young individuals with TBI are effectively served in community settings. Accurate identification of elderly nursing home residents with TBI is problematic. There are concerns about the appropriateness of long-term nursing home services for individuals with TBI, particularly younger adults.

IV. TBI Needs and Resources Assessment Methodology

Work on Vermont's Traumatic Brain Injury needs assessment took place over a 13-month period, from July 2002 through July 2003. The TBI Program contracted with Flint Springs Consulting, a Vermont-based consulting group, to conduct the needs assessment.

Advisory Board and Steering Committee

Two groups were instrumental in conducting the TBI Needs Assessment. A five member Steering Committee, which met ten times over the course of the assessment project, served as the sounding board to the consultants, providing critical input throughout the process and reviewing materials prior to presentation to the full Advisory Board.

A TBI Advisory Board comprised of 24 members was created and convened three times during the needs assessment process. Nine members (38%) are individuals with TBI /family members with mild, moderate, and severe brain injuries. The remaining members are health care and social service providers, as well as representatives of state agencies and disability advocacy organizations. Members come from rural and urban areas throughout Vermont. Participants were offered a \$50 stipend for each meeting and reimbursement for transportation and attendant services if their time and expenses were not covered as part of their employment.

The role of the Advisory Board during the needs assessment process was: to provide feedback on the proposed assessment methodology; to provide guidance in data collection, including development of the survey mailing list, identification of key informants and other sources of information; to provide guidance in tailoring methodology to obtain information from individuals with various levels of TBI; to review summaries of quantitative and qualitative data to ensure that data adequately addressed each area of need; and to review the draft assessment report. The TBI Advisory Board will continue to advise the TBI Program staff during the creation of a plan to address priority areas for action identified in the needs assessment.

The Flint Springs Consulting team carried out all research activities and supported all activities of the Steering Committee and the Advisory Board.

Areas of Focus

The needs assessment was designed to gather information in five key areas of focus:

1. How prevalent is TBI in Vermont?
2. How do individuals with TBI get into the system of support services?

3. What do individuals with TBI and their families need?
4. What barriers prevent individuals with TBI and their families from using existing services?
5. How do we know if the service system is meeting the needs of individuals with TBI and their families?

Data Collection

The needs assessment employed three complementary data collection strategies to gather information about a variety of questions in each area of focus. Surveys of individuals with TBI and service providers were conducted to collect quantitative data. Two methods were utilized to gather qualitative data: focus groups were held with individuals with TBI/family members, and individual key informant interviews were conducted with professionals and advocates. The qualitative methods informed the development of surveys and provided a depth of information that cannot be obtained through surveys. *(See Appendices A, B, and C for Key Informant Interview, Focus Group, and Survey Summaries.)*

Table 1 shows data collection strategies, participant types for each strategy, and the type of information gathered by each strategy.

Table 1: Data Collection Strategies

Data Collection Strategy	Participants	Type of Information Gathered
Key Informant Interviews <i>(used also to identify key issues for inclusion in survey)</i>	Service providers, advocates, administrators	Identifying undiagnosed individuals with TBI Paths of entry into TBI services Funding sources for TBI services Services needed for TBI Services available in Vermont Barriers to access & use of services Outcome measures
Focus Groups <i>(used also to identify key issues for inclusion in survey)</i>	Individuals with TBI Family members	Services needed for TBI Services available in Vermont Service coordination Barriers to access & use of services Outcome measures
Survivor Survey	Individuals with TBI Family members	Services needed for TBI Service coordination Barriers to access & use of services
Provider Survey	TBI service providers	Services currently available in Vermont Coordination of services Barriers to access & use of services Appropriate outcome measures & collection of outcome data

The focus group study targeted three populations: children and youth up to age 25 with injury occurring prior to age 18; adults ages 26 to 59; and elders ages 60 and older. Three individual telephone interviews were conducted in lieu of the elders group in response to recruitment challenges for that group. The children and adult groups were held as planned. In total, sixteen (16) individuals with TBI and family members participated in the focus groups and individual interviews.

Twenty-four (24) key informants representing a variety of health care, service provider, and advocacy perspectives were interviewed, primarily by telephone, using a structured set of questions.

Separate survey tools were developed for individuals with TBI and service providers. The Health Resources and Services Administration's (HRSA) *Traumatic Brain Injury Needs and Resources Assessment Tool* provided a starting place for development of the Vermont survey tools. In addition, the findings from the focus groups and key informant interviews, conducted prior to the surveys, informed the development of the survey questions. The Survivor Survey was field tested by several individuals with TBI, and revised as indicated by the pilot. As a final step, the survey tools were approved for use by the Agency of Human Services Institutional Review Board.

In total, 2,544 surveys were distributed to individuals with TBI and service providers, with an overall response rate of 14.7% (373 surveys). Of the 1,419 surveys distributed to individuals with TBI, 190 completed surveys were returned (13.4%). Of the 1,125 surveys distributed to providers, 183 completed surveys were returned (16.3%)⁸. Survivor Surveys were returned anonymously, and Provider Surveys included agency name only. Because a broad-brush approach to distributing the surveys was used, it is likely that some individuals received more than one copy of the survey. To prevent double counting, surveys included an instruction to complete the survey only once. A postage-paid return envelope was included with each survey.

Distribution of the Survivor Survey utilized both direct mailing of surveys to individuals on the TBI Program annual conference mailing list and on their database, and distribution to individuals through a wide variety of providers and organizations who serve individuals with TBI. Instructions for the Survivor Survey included a phone and e-mail contact for individuals who needed to receive the survey in another format or required assistance in completing the survey. For those in the latter group, a member of the consulting team conducted the survey by phone.

Distribution of the Provider Survey also utilized a combination of TBI Program mailing lists and identification of a wide variety of provider agencies and organizations. Both direct service staff and agency administrators were asked to respond to the survey.

⁸ Descriptions of survivor demographic characteristics and provider characteristics (e.g., agency types represented) are provided in the summary found in Appendix C.

Lack of information about prevalence and incidence

The needs assessment set out to gather information about the prevalence and incidence of TBI in Vermont. In particular, it was hoped that more would be learned about the severity, demographics, and causation of TBI statewide. Key informants were asked for suggestions of data sources – beyond hospital data currently collected – to get at prevalence and incidence of TBI in Vermont. In particular, sources were sought to identify individuals who have experienced mild to moderate traumatic brain injuries but who have been misdiagnosed or undiagnosed. While informants did offer suggestions about a variety of potential sources of data, most of the data sources did not turn out to gather TBI data in a consistent or systematic way, if at all. Lacking a TBI registry or unique identifier system, some individuals would invariably be counted and reported by more than one source, and others would not be counted at all. As a result, the needs assessment learned more about the *need* for assessment, diagnosis, and data reporting than it was able to learn about actual prevalence and incidence.

V. TBI Needs and Resources Assessment Findings

How do individuals with TBI get into the system of support services?

Key informant interviews provided the most extensive information on paths of entry into services and supports for brain injury. The majority of the informants described pathways to their own services. The only nexus for TBI services that emerged was the TBI Waiver Program, which serves only individuals with moderate to severe TBI. The conclusion may be drawn that there is no actual system of TBI services in Vermont, as several informants so stated.

Based on information provided by the key informant interviews, the paths of entry into primary services and supports for brain injury can be described as follows:

- **Hospital and Rehabilitation Services:** Hospitals play a key role in both providing services and referring patients to other services upon discharge. Emergency medical services are often the entry point following a traumatic injury. Hospitals generally serve as the primary referral source for rehabilitation care. In cases of less severe trauma, primary care providers play a key role in identifying TBI and referring patients to rehabilitation. Other health care providers serving as the initial referral into TBI services include chiropractors, massage therapists, and ophthalmologists.
- **Long-Term Care:** Services such as the Home and Community Based Waiver, nursing homes, and home health care are generally accessed by individuals through hospital referrals. The TBI Waiver Program often serves as a link between hospital and home-based services. In some cases, primary care providers refer individuals to long-term care services.
- **Psychological Services/Evaluation:** Psychologist informants noted that referrals for these services come from a wide range of sources, including: hospital social workers, schools, Social and Rehabilitation Services (SRS), primary care providers, outpatient occupational and physical therapists, TBI Waiver Program, home health, other mental health providers, attorneys, insurance companies, Workers Compensation, and Vocational Rehabilitation.
- **Children's Services:** Schools play a critical role in providing services and making referrals for children with TBI. Evaluation within the educational setting is an important gate of entry, and can be requested by parents, special educators, and psychologists. Athletic coaches are becoming more aware of TBI and are beginning to refer student athletes to primary care providers and emergency rooms for evaluation after sports injuries. Many children enter the system through a visit to the school nurse. Other entry points for children to

receive TBI services include: Early Essential Education, psychologists, SRS, Children with Special Health Needs, Parent Support Organizations, school-based I-team, pediatricians, and Developmental Services.

Individuals with TBI might also find their way into services through other programs, such as DVR and Workers Compensation. One informant noted that although DVR is the focal point for TBI services, people continue to appear inappropriately in the mental health system; this is a problem for people with old injuries and a frustration for mental health providers. If an individual with TBI qualifies for mental health or developmental services, they receive individualized services from Department of Developmental and Mental Health Services (DDMHS) designated agencies, including referrals to TBI specific services as appropriate and available.

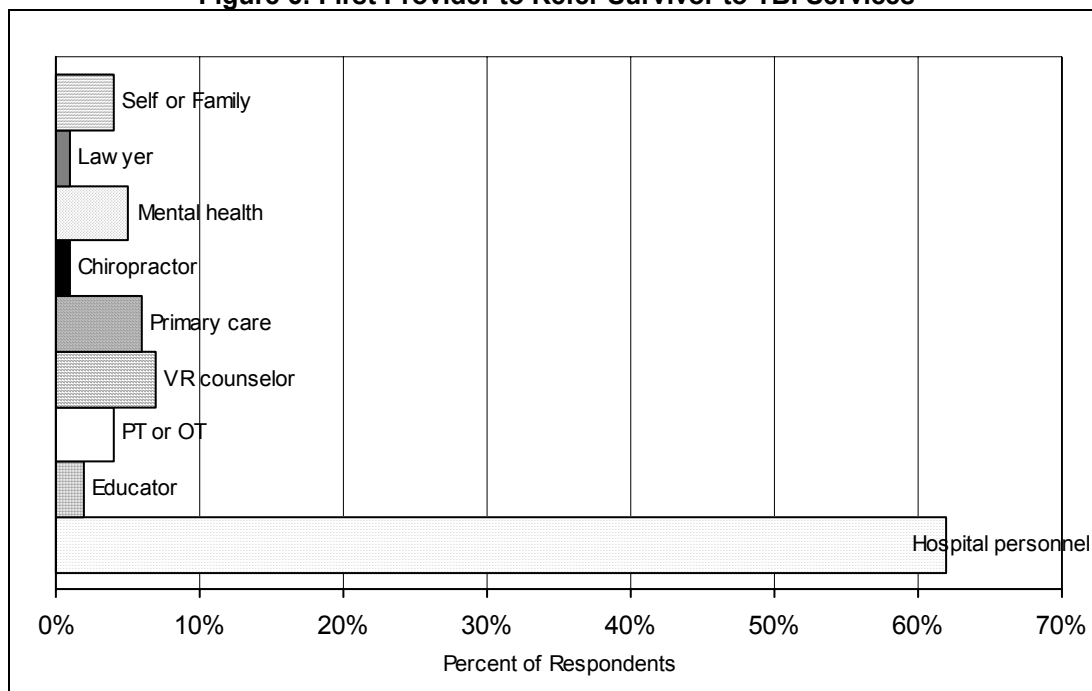
In nursing homes and residential care facilities, a change in a resident's condition for any reason, including TBI, triggers new assessment and care planning, which includes TBI services as appropriate.

The single informant who addressed the issues of individuals with TBI under the custody of the Department of Corrections (DOC) suggested that DOC staff do not have adequate training and knowledge to identify individuals with TBI who do not self-identify. Often, advocates from the Prisoner's Rights Project suggest services for offenders with TBI.

Self-referral was also noted as an important avenue into services for many individuals with TBI, particularly those with moderate and mild injuries. For example, one informant noted that individuals with TBI or their family members find services by "calling anybody and everybody trying to figure it out."

An important theme emerging from key informant interviews was that individuals with severe brain injury are more likely to be referred to and receive TBI services than those with moderate and mild injuries. Indeed, in spite of considerable efforts to distribute the Survivor Survey to persons with all levels of brain injury severity, 76% of the respondents had a severe injury; indicating that individuals with initially severe rather than mild or moderate injuries were known to providers and advocates distributing surveys. Not surprisingly, then, 78% of respondents learned of their injury through the hospital. Of respondents with severe injuries, 83% learned of their TBI through hospital personnel. Even 63% of those with initially moderate, and 55% of those with initially mild injuries learned of their TBI through hospital staff. Additional sources of information about TBI for those with moderate and mild injuries were family doctors and pediatricians. The majority of survey respondents were first referred to services by hospital personnel (see Figure 6).

Figure 6: First Provider to Refer Survivor to TBI Services



Sources of funding are critical to accessing TBI services and supports. Key informants identified the TBI Waiver as an invaluable source of funding for adults with TBI. Aside from the Waiver, there is no funding for daily living needs and supports, skills training, and “relearning how to live.” Waiver services are only available for Medicaid-eligible individuals with severe TBI. As one informant said:

In Vermont, if you are Medicaid eligible and have severe TBI, the TBI Waiver is phenomenal. But if you are not Medicaid eligible and not severe, you can’t buy case management/coordination even if you have money.⁹

Medicaid eligibility also opens the door to the Home and Community Based Waiver for the Aging and Disabled (HCBW), administered through the Department of Aging and Disabilities (DAD), which provides in-home and community based services for adults.

Medicare pays for short-term skilled care in nursing homes. It also covers limited in-home care for homebound individuals, including nursing and rehabilitation therapies, provided through home health agencies.

Private health care insurance covers the cost of TBI services for some children and adults. Key informants noted that there are limits to the coverage, and it varies widely depending on policies and carrier. Private insurance covers medically necessary services and often places limitations on coverage for rehabilitation services (e.g., may not cover cognitive rehabilitation).

⁹ Throughout this report, verbatim quotes from participants appear in italics.

DVR funds employment-related services and may help with assistive technology, housing, and modified vans when employment is a goal. One informant noted that DVR funds are most useful for individuals with moderate and mild TBI, and that DVR can provide employment supports and case management for a limited time only.

In addition to Medicaid and private insurance, children's TBI services may be covered by Special Education, Children with Special Health Needs, Early Essential Education, or the Family, Infant and Toddler Program.

Respondents to the Survivor Survey were asked how they covered the costs of TBI services and supports. Multiple funding sources were identified. Among them the most frequently identified sources of payment were Medicaid, personal funds, and Medicare (see Table 2). Personal funds may be used by individuals with TBI to cover services not funded by existing programs or to buy services when they do not qualify for other service funding.

Table 2: Survivor Survey Respondents' Report of Services Funding Sources

Sources of funding for services	Frequency	Percent
Medicaid*	102	54%
Personal funds	82	43%
Medicare	76	40%
Private insurance	64	34%
TBI Waiver	54	28%
Vocational Rehabilitation	44	23%
Personal loans from family/friends	35	18%
Special Education funds	16	8%
Department of Employment & Training	11	6%
Children with Special Health Needs	9	5%
Veteran's Administration	10	5%
Workers Compensation	7	4%
Family, Infant & Toddler	5	3%
Early Essential Education (EEE)	4	2%

*Note: Of the 102 respondents receiving Medicaid, 43 were also on the TBI Waiver.

What services do individuals with TBI and their families need?

To determine service and support needs for individuals with TBI and their families, the needs assessment began by asking key informants to identify specific service needs. Based on these responses, focus group participants were asked in a more directed manner to identify critical needs and gaps in services. Finally, through the surveys individuals with TBI and providers were asked about access to critical services identified by the focus groups. Individuals with TBI were asked to name the "three most important services" and the "one most important service missing" from the services they currently receive or have received in the past. Providers were asked to name the "three most significant brain-injury related services that are missing from the service system for individuals with TBI and their families."

The following summary presents results in terms of service and support needs identified as most significant. First, needs identified by all three sources of information – key informant interviews, focus groups and surveys – will be reported. These include:

- Employment, including long-term employment supports
- Family supports and respite
- Home-based services (life skills aides, personal care attendants, home health aides, nursing care)
- Information and referral (accurate, consistent information to assist with accessing appropriate services)
- Case management or service coordination
- TBI Waiver or Waiver-type services (including case management, funds for TBI services and supports)
- Trained and knowledgeable health care, mental health, and direct care providers.
- Long-term services and supports (including rehabilitation therapies, case management and home based services without durational limits, and ongoing employment supports)
- Transportation

Second, needs identified as significant by one or two of the sources of information will be reported separately. These needs include:

- Rehabilitation therapies
- Financial assistance for daily living and services
- Social opportunities, support groups, and counseling
- Flexible systems and funding (including eligibility barriers and insurance limits)
- Public education and awareness, including prevention

(1) Service and support needs identified by all information sources

Employment and long-term supports were identified as critical in various ways. Both key informants and focus group participants talked about employment issues. Key informants noted that individuals with TBI needed assistance with employment for the long term, not just for the short term. Focus group participants talked about problems that arose when they pushed themselves to return to work too soon, for too many hours, and to jobs that they could no longer perform. They expressed frustration with no longer being able to do work they had previously done and their desire to do meaningful work. Focus group participants also spoke of the need for assistance in negotiating issues in the workplace, including identifying and getting appropriate accommodations, the need to educate employers, and the need for job training.

Survivor Survey respondents identified work as the area of their lives most impacted by their TBI. As can be seen in Table 3, overall 82% of individuals with TBI reported that their brain injury affected their work.

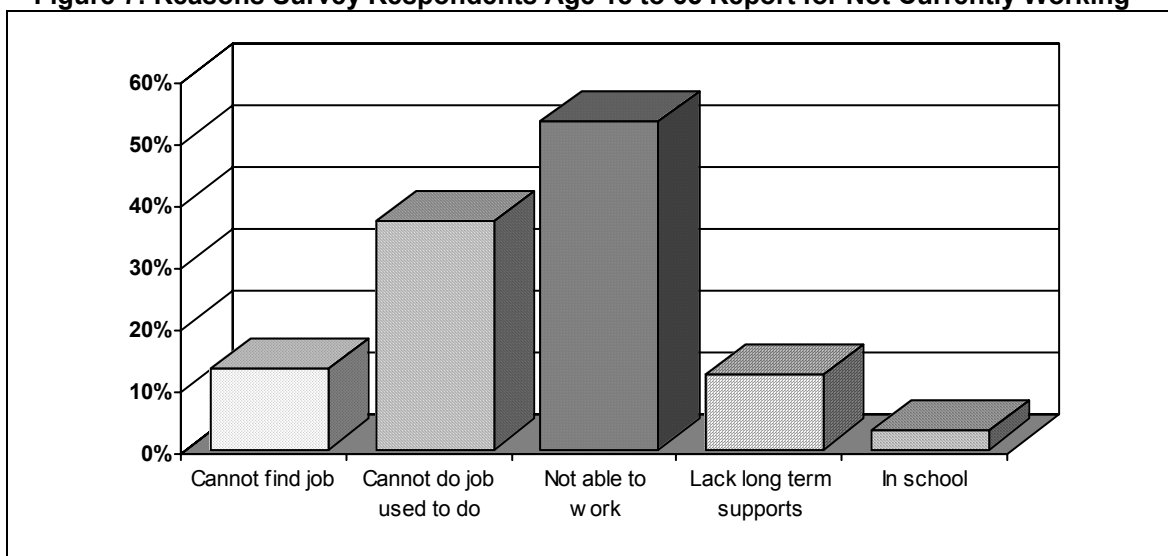
Table 3: Survivor Survey Respondents' Report of Areas of Life Changed by Self-Reported TBI Severity

Area of Life Changed by TBI	Level of TBI Severity			Total of All Individuals with TBI
	Severe	Moderate	Mild	
<u>Work:</u>				
Initial injury	85%	4%	82%	82%
Current severity	85%	86%	65%	
<u>Friendships:</u>				
Initial injury	80%	79%	73%	76%
Current severity	85%	79%	65%	
<u>State of mind/ psychological outlook</u>				
Initial injury	78%	68%	82%	76%
Current severity	89%	75%	62%	
<u>Health:</u>				
Initial injury	65%	47%	91%	62%
Current severity	82%	63%	19%	
<u>Marriage:</u>				
Initial injury	58%	63%	64%	58%
Current severity	68%	56%	46%	
<u>Living situation:</u>				
Initial injury	61%	42%	27%	54%
Current severity	81%	48%	19%	

Two thirds (66%) of the Survivor Survey respondents were currently not working. Of respondents with an initially severe TBI, 70% were unemployed as compared to 40% of respondents with an initially moderate injury.

When asked why they were not working, the majority of respondents aged 18 to 65 years of age said they were not able to work (see Figure 7). Another third of the respondents said they could no longer do the job they “used to do.”

Figure 7: Reasons Survey Respondents Age 18 to 65 Report for Not Currently Working



When asked about the “three most important services you get now or that you have received in the past,” Survivor Survey respondents identified assistance with job skills and vocational rehabilitation as among the top four important services. When asked to name the most important missing services, Survivor Survey respondents most frequently said help with finding and keeping a job. Survey respondents said they needed:

Help finding employment that I could do.

Help to find a job and keep it.

Services to figure out how to get a job in a career you are not educated for.

Family supports and respite were frequently cited by key informants as needed for families and caregivers of individuals with TBI. Focus group participants also spoke about the need for support for families through support groups, respite care, and a range of other types of supports. Focus group participants described feelings of isolation and being alone with their family members’ head injury, especially in rural areas. Support groups were cited as a critical need for family members, as well as for individuals with TBI. Families need a variety of supports, including counseling to identify and work through issues. Some families are not up to the task of supporting a family member with a brain injury and require intervention and even abuse prevention. Respite services were seen as important for both individuals with TBI and family members, for example, after-school and summer programs for children with brain injuries.

Family members completing the Survivor Survey on behalf of the individual with TBI in their family were asked to identify the “one most important service that you need.” The most frequently mentioned needs for family members were support groups, help coping, and respite care. Survey respondents commented:

As the spouse of a BI survivor I would say the most important service that I need (and is lacking) is a support group for caregivers.

Counseling on how to cope with extreme behavior issues manifested in a family member with TBI. This is a very serious issue.

To have some sort of support group available that wouldn’t require a lot of travel.

A day in the week entirely to myself, without worrying about what is happening with my son.

... I look at it from my side and there’s got to be some support for families who have TBI survivors in their homes because, you know, we do give a lot of our time, and it’s taken a big toll. But it’s done with love and because we have hope for the future.

Home-based services, including life skills aides (LSA), personal care attendants (PCA), home health aides, and nursing care were seen as the second most important service by respondents to the Survivor Survey. As one respondent said, “*Staff to assist with the things I can’t do independently.*” Key informants frequently said that life skills aides were important to provide one-to-one assistance and training for individuals with TBI on organization, time management, activities of daily living, and access to community activities. Focus group participants were especially concerned about the training of direct care workers that provide home-based services and supports.

Information and referral was identified by both key informants and focus group participants. Focus group participants were hungry for information. They wanted to get information earlier, and they wanted it to be more specific and readily available from sources in Vermont. The nature of information needs change over time. At first, individuals with TBI and family members need information about brain injury, including what to expect in terms of functioning. As individuals with TBI progress, they and their family members need information about services and resources. Focus group participants spoke about not realizing they need services because they were unaware of the existence of services that might have been of benefit. Some focus group participants spoke about the profound negative impact of receiving misinformation and “bad advice” on the eligibility and availability of services, as well as legal and financial matters. As focus group participants commented:

Information. I crave information.

I mean, three days after the accident, me being as ignorant as I was, I bring her potty to the hospital thinking she’s about to get up and use her potty. Nobody told us.

I remember vividly going to the local social welfare office to do the paperwork to get my mother on Medicaid. I asked the worker if there was a program for people with brain injuries and she said no. When we found out later about the TBI Waiver Program, we were beside ourselves that the state didn’t even know about its own program.

You’re pretty much on your own. It’s been five years (since my child’s injury) and I think that I know more about a brain injury than anybody that’s ever worked with me.

Following up on the focus group participants’ strongly stated need for information, the Survivor Survey asked respondents whether they had ever received information about three topic areas: legal and financial matters; services for brain injury; and information about what brain injury is and what to expect. The respondents were next asked if any of these three types of information would be helpful to them now.

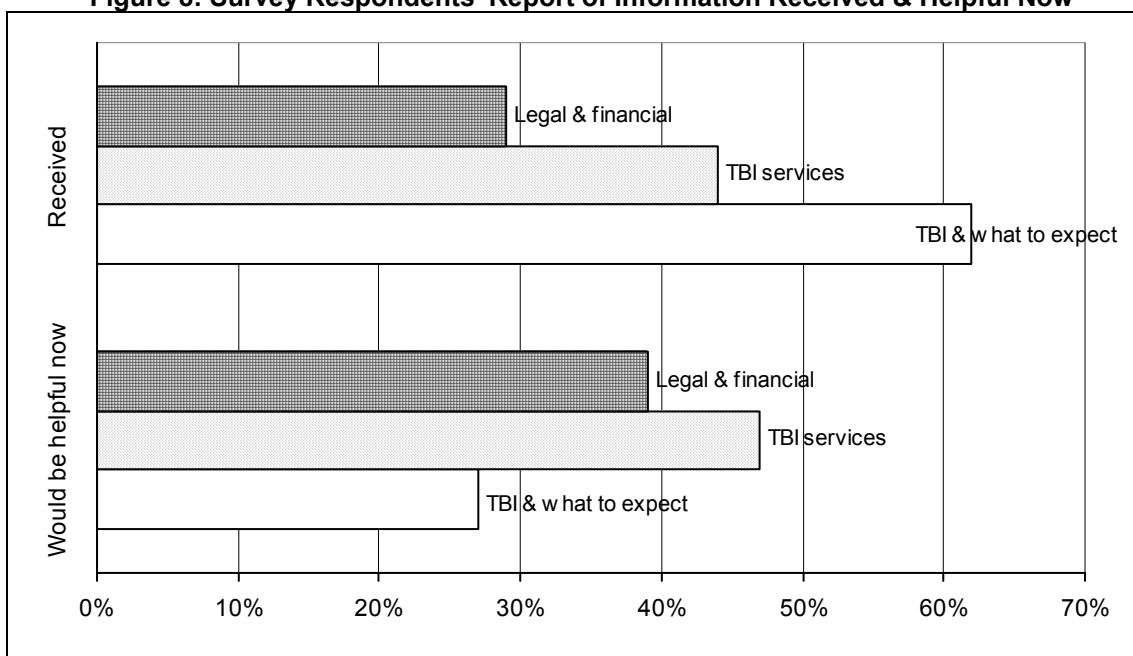
The majority of respondents had received information on TBI; still, one third said this information would helpful to them now (see Figure 8). This supports the focus group

finding that information needs continue as individuals with TBI recover. Less than half of the survey respondents had ever received information on TBI services, and nearly half would find such information helpful now. Few respondents had received legal and financial information, and more than a third would find such information helpful now. Survey respondents want:

Information about how to access TBI rehab services – cognitive (this is very hard info to get); takes months of turning over every rock to even find out where and what cognitive rehab is.

Information about services and how to access especially in a timely manner when you need it most.

Figure 8: Survey Respondents' Report of Information Received & Helpful Now



Case management or service coordination was one of the most frequently mentioned service needs among key informants. For focus group participants, case management was the most frequently identified need. Case management was described as very helpful by those who received it. The lack of ongoing, consistent case management was identified as a major barrier to receiving needed services and to achieving a satisfactory quality of life.

Focus group participants wanted a type of case management that goes well beyond medical case management typically provided in acute, sub-acute, and rehabilitation settings. These individuals with TBI and their family members wanted comprehensive case management that helps identify services and navigate the service delivery system, as well as assist in the school setting, with financial matters, work-related issues, obtaining needed accommodations, and other matters of daily living. Case managers were seen as

serving a critical role in coordinating a sometimes bewildering array of health and social services in a highly fragmented service delivery system.

Case management currently available, according to focus group participants, is typically limited to the specific system or facility in which the case manager works (e.g., a hospital, nursing home, insurance company, rehabilitation facility, or school). Case management may not extend beyond the services available in the case manager's own sphere, and case managers change as individuals with TBI move from one facility or system to the next. Individuals with TBI wanted case management that is ongoing, consistent, and moves with the individual as she or he progresses from hospital, to rehabilitation, to community based settings and independent living.

As individuals with TBI make progress in their recovery, they often “graduate” from the programs that provide case management, leaving them without assistance on an ongoing basis. For individuals with mild and moderate brain injuries, case management may be unavailable at any time post-injury. Focus group participants commented that case management may be needed many years post-injury and even life-long.

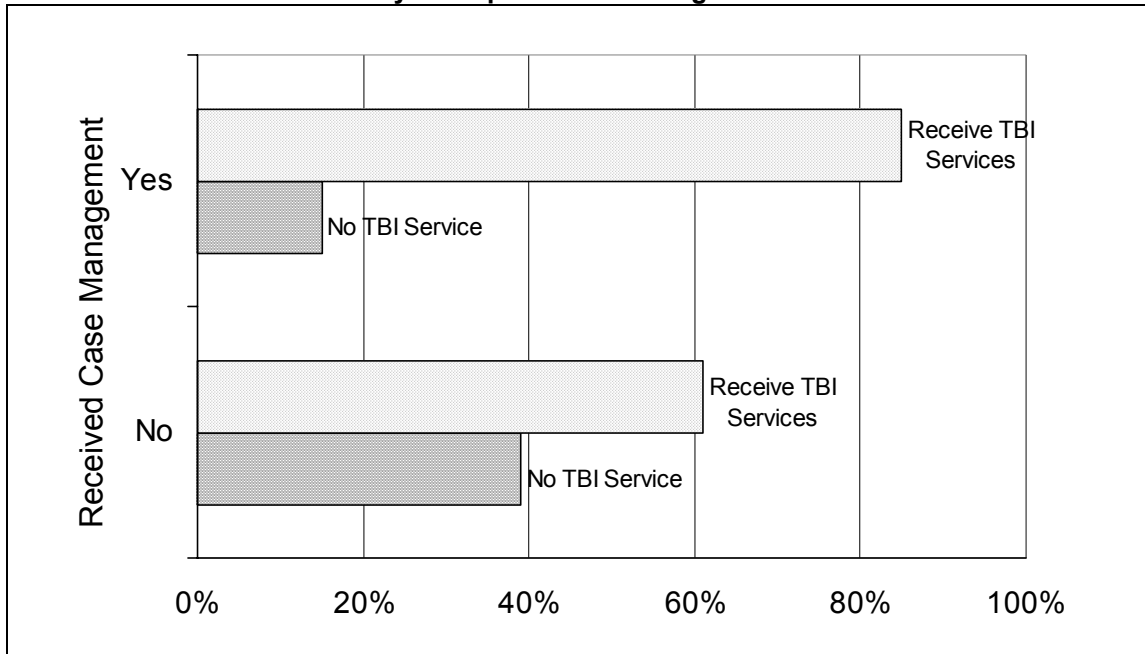
Focus group participants' comments on the need for case management included:

The most helpful [service] is when I got, actually got a case manager. Even though this was 25 years after my car accident, you know, but it was when somebody really helped me get my life together 'cause it was all falling apart...the only problem was I only got them after I was in [psychiatric inpatient unit]. But I think way before that...they've got to figure out a way, if you have a brain injury to assign a case manager to review your case and see what you need. Have it done before you end up in a psych ward, or worse.

Some of the problems exist because those services aren't available, like case management, having someone that will go with you through the whole process. There are times that you don't understand what you need or where those services are, and I think it would benefit people to, right after a TBI, to have someone assigned to them to work with them through the process.

Survivor Survey respondents were asked if they had ever received case management or help coordinating services. Overall, 61% of respondents said they had received case management at some point after their brain injury. Survey respondents were also asked if they had received services specifically for TBI. Nearly three quarters of the respondents had received TBI services, regardless of the initial severity of their injury. As shown in Figure 9, the vast majority of respondents who received case management also received TBI services. Meanwhile, nearly 40% of respondents who did not receive case management also did not receive TBI services. This finding supports comments made by both key informants and focus group participants indicating that case management is critical to receiving TBI services.

Figure 9: Survey Respondents' Report of Receiving TBI Services by Receipt of Case Management



TBI Waiver or Waiver-type Services were often mentioned by key informants as important for individuals with TBI and their families. These services include case management, life skills aides, crisis support, counseling, and a team approach. Focus group participants who were ineligible for Waiver services due to age (too young or too old), severity of injury (mild or moderate), Medicaid ineligibility, or pre-existing injury expressed a need for these types of services. Several participants noted that the length of time people can stay on the TBI Waiver was insufficient to meet their needs. Waiver services and Waiver-type services were needed not just during rehabilitation, but on an ongoing basis as well. Key informants echoed these concerns, frequently stating that there is a need for expanded eligibility for the Waiver.

Provider Survey respondents identified the TBI Waiver Program, and its staff, as the most successful element of the current Vermont system of services for individuals with TBI and their families. These same providers saw limits in eligibility for Waiver services as one of the most significant missing links in the TBI service system.

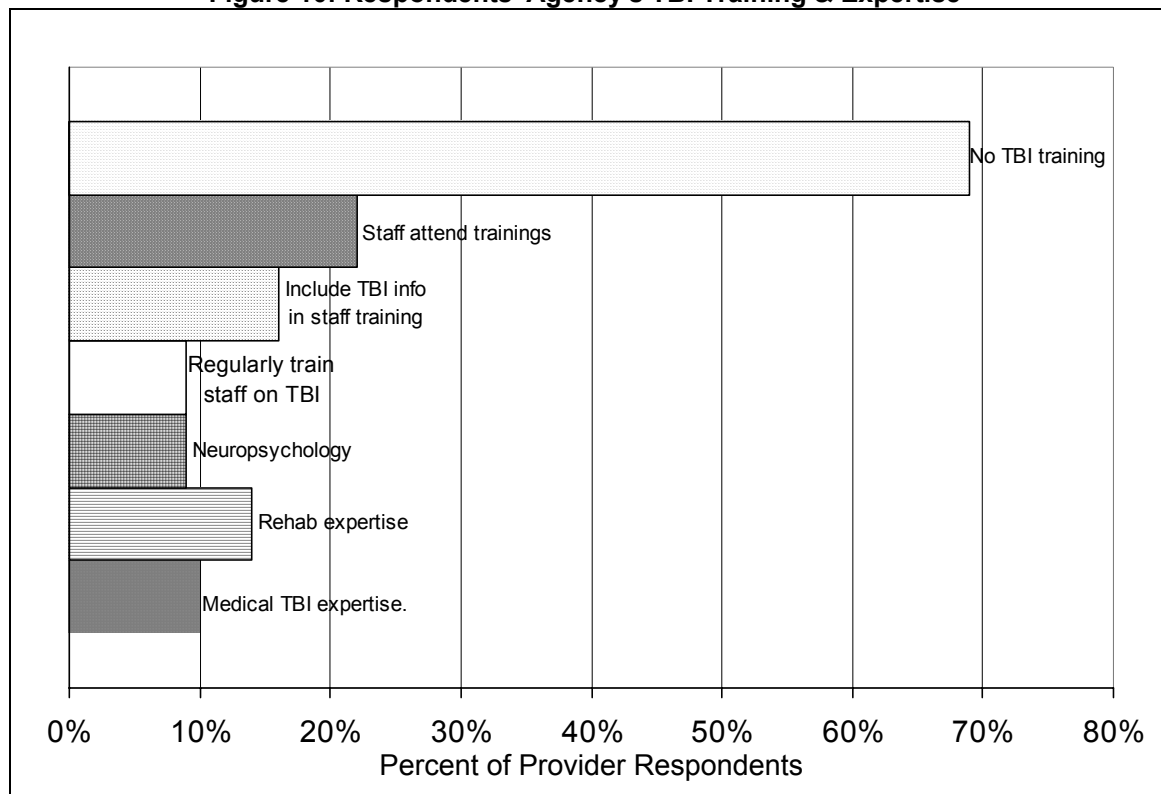
Survivor Survey respondents identified the types of services provided by the TBI Waiver Program as most important to meeting their needs, including: rehabilitation therapies; home-based care; funding for services; job skills; vocational rehabilitation and case management. Some individuals with TBI specifically named the TBI Waiver Program as one of the three most important services they received.

Trained and knowledgeable health care, mental health, and direct care providers were seen as essential to meeting the needs of individuals with TBI and their families by all groups. Key informants frequently noted that knowledge must begin with trained professionals who can provide accurate diagnoses to ensure appropriate treatment. Evaluation and assessments, particularly by neuropsychologists, were identified as essential to creating individualized service plans for individuals with TBI. In addition, key informants felt a range of professionals (e.g., educators, pediatricians, primary care physicians, psychologists) need TBI training so that they might be better able to screen for mild and moderate TBI and refer persons for diagnosis and treatment.

Focus group participants described a variety of problems caused by the lack of knowledge on the part of medical, educational, and social service providers. The participants suggested training on TBI for such providers so that they can identify TBI, and understand that recovery is a long-term process in which individuals with TBI can make steady progress.

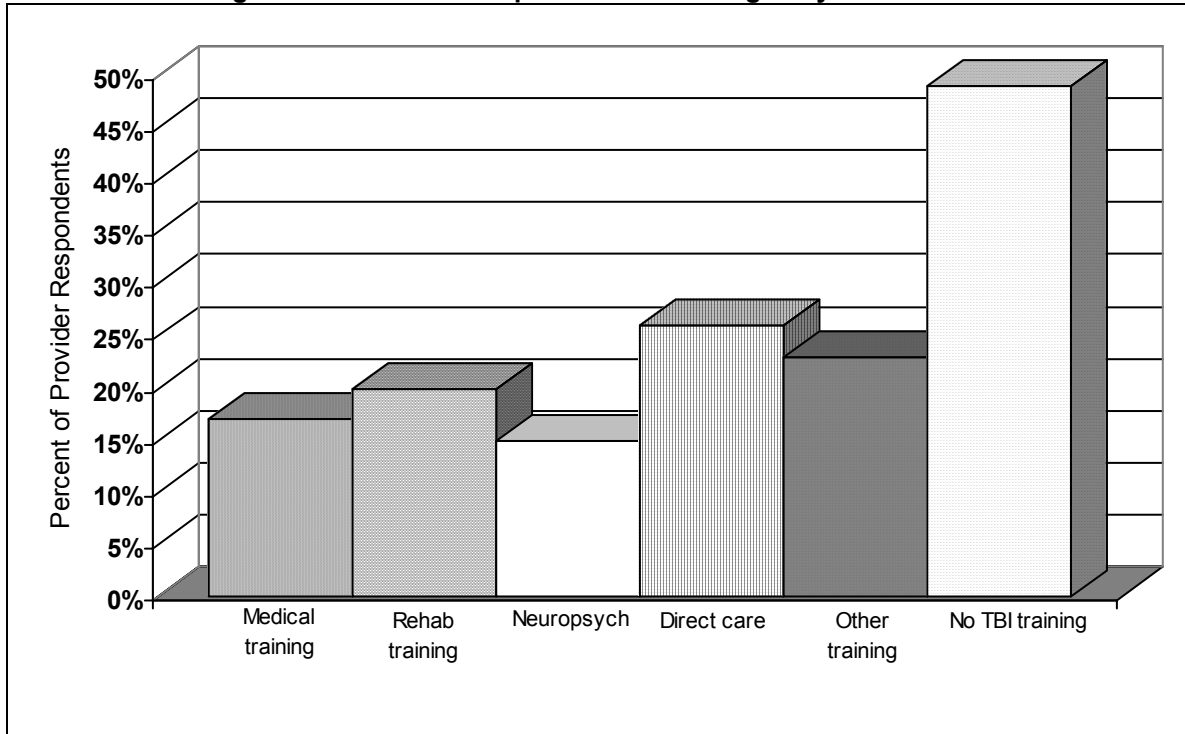
Responses from the Provider Survey underscore the need for training among service providers across all professions. The Provider Survey asked about training and expertise in two ways. First, respondents were asked what training or expertise their agency staff either bring to or receive through the agency. The vast majority of agencies represented by survey respondents did not have staff with TBI expertise and did not provide TBI training for staff (see Figure 10).

Figure 10: Respondents' Agency's TBI Training & Expertise



Providers were also asked to identify the types of specialized TBI training they had personally received. As shown in Figure 11, nearly half of the survey respondents had not received any specialized TBI training. About one quarter of the “other” training involved attendance at the annual TBI conference.

Figure 11: Providers' Report of TBI Training They Received



Providers working in home health agencies were the most likely to have received specialized TBI training (see Table 4), while those in agencies providing residential care and information and referral were least likely to have received TBI training.

Table 4: Providers' Report of Receiving TBI Training by Their Agency's Services

Services Provided by Respondents' Agency	Number of Respondents Receiving TBI Training	Percent of Respondents whose Agency Provides these Services
Home Health	17	81%
Substance Abuse treatment	2	67%
Rehabilitation	28	65%
Mental health/Developmental Services	14	52%
Educational	13	52%
Advocacy	11	50%
Medical	13	48%
Employment/vocational	16	43%
Information & Referral	7	37%
Residential care	6	33%

As shown in Table 5, providers working in community based, day treatment, and residential settings were least likely to have received TBI training, while those in outpatient and home-based care settings were most likely to have received training.

Table 5: Providers' Report of Receiving TBI Training by Agency Service Setting

Service Settings of Respondents' Agency	Number of Respondents Receiving TBI Training	Percent of Respondents whose Agency Provides these Services
Outpatient	30	65%
Home-based care	27	60%
School	8	57%
Inpatient	27	56%
Office setting	6	55%
Residential program	10	40%
Day treatment	6	40%
Community based setting	25	39%

Long-term services and supports including rehabilitation therapies, case management, and home-based services were identified as a need by many key informants. They noted that services are often available for a limited time post-injury, but individuals with TBI need these services often for a lifetime. Focus group participants also discussed the need for services and supports to be available over the long term, not just during the relatively brief period they are often available post-injury. Service providers responding to the Provider Survey listed the need for long-term services and supports as the most significant missing link in the TBI service system (see Table 6).

Table 6: Providers' Most Frequently Identified Gaps in TBI Services

TBI Service System Gaps	Frequency	Percent
Long-term services and support	39	21%
Limited program eligibility	28	15%
Limited availability of case management	23	13%
Lack of TBI training among professionals	20	11%
Limited funds for range of service needs	18	10%
Need for evaluation and assessment of TBI	10	6%

Transportation was cited by both key informants and focus group participants as critical to accessing services and supports. Focus group participants noted that transportation is needed by individuals with TBI who live independently, as well as those residing with family members whose other obligations limit their availability to provide transportation. Survivor Survey respondents frequently cited transportation as an important service and as missing from the services they receive. For example:

Transportation to many appointments – local and out of the area

I never got transportation to work. I have to rely on my mother.

Reliable transportation – instead of having to “piece meal” it.

(2) Needs identified by survey respondents as most important

When asked to name the most important services they received, individuals with TBI most frequently cited rehabilitation therapies, home-based services, and sources of funding for services and daily living (see Table 7). Respondents to the Provider Survey identified rehabilitation services as one of the most successful elements of the current TBI service system.

Table 7: Services Survivor Survey Respondents Named Most Important

Services Identified as Most Important by Respondents	Frequency	Percent
Rehab. Therapies (OT, PT, speech)	43	23%
Home-based care (LSA, PCA, etc.)	31	16%
Sources of funding (insurance, SSI, etc.)	30	16%
Voc Rehab/job skills	25	13%
Case management/service coordination	16	8%
Assistance with school, education	13	7%
Transportation	8	4%
TBI Waiver Program	7	4%

In response to the question asking what services were missing, Survivor Survey respondents most often said they were lacking help finding and keeping a job, financial assistance, social opportunities, and support/counseling (see Table 8). As one individual with TBI said, *“I have no one to talk to.”* The value of support groups and counseling was reinforced by Provider Survey respondents.

Table 8: Services Most Frequently Identified as Missing by Survivor Survey Respondents

Most Important Missing Service	Frequency	Percent
Help finding and keeping a job	12	6%
Financial assistance	11	6%
Someone to talk with/social opportunities	9	5%
Psychological support/counseling	8	4%
Transportation	8	4%
Service coordination	6	3%

Provider Survey respondents identified limited program eligibility (due to age, cause of TBI, and time since injury) as one of the most important gaps in the current service system (see Table 6).

(3) Needs identified by focus group participants as most important

Additional needs identified by focus group participants included advocates to help access services and model self-advocacy, and information and assistance during times of transition. Focus group participants said that advocates are needed in a variety of settings and with many issues – workplace accommodations, at school, dealing with insurances, eligibility, and benefits, with assistive technology, getting needed services from health

care providers, and so on. Participants noted that advocates often achieve better results than individuals with TBI or family members. Advocates also model effective practices that individuals with TBI and family members learn to use in self-advocacy. Some of the participants' comments included:

Having the whole picture of support, feeling like I don't have to do everything, be everything, you know, for my child. That I actually had an advocate that was on my side that I wasn't fighting for money issues or I wasn't fighting. I think that would be more important...because then I would be at peace.

We only got this far because she had four determined children. Otherwise she'd still be in a nursing home.

Focus group participants described many situations illustrating the point that transitions are difficult for individuals with TBI and family members. For individuals with TBI, every change to a new environment may present challenges. Participants felt more support was needed when individuals move from one institutional setting to the next, from out-of-state facilities back to Vermont, and from rehabilitation facilities to nursing homes, residential care, or home. In some instances, participants spoke of poorly managed transitions with little or no support that aggravated the individual with TBI's need for consistency promoting regression rather than progress. Younger people and their families face additional challenges such as shifting from structured school environment to an unstructured summer environment each year. Participants spoke of the profound negative impact the lack of information, support, and consistent case management during these times of transition, when they need such services and supports the most. For example:

I think the hospitals need to be a better source of information for people with brain injuries. They sort of send us home pretty vague as to what's going to happen and what's going on. They tell you your home health facility will take care of everything. Your home health facility doesn't take care of everything. You're pretty much on your own.

The changes challenge a brain-injured person. A new teacher, a new room. If you get a new couch it throws them off a little.

I was surprised at just how much energy went into getting used to a new environment. It took so much out of me to just get used to that new spot.

(4) Needs identified by key informants as most important

Issues identified by most key informants were consistent with those named by survey respondents and focus group participants. The one issue strongly emphasized by key informants was the need for public education to increase awareness and understanding of TBI. This was seen as closely linked to improved data collection and prevention efforts,

as well. In several related comments, key informants emphasized the need for accurate diagnosis and assessment of TBI so that individuals with brain injuries were appropriately identified and provided with needed services and supports. Many informants felt that diagnosis depended first on public awareness of TBI, and second on well trained providers.

What barriers prevent individuals with TBI and their families from finding and using services?

Key informants and focus group participants identified a range of barriers to using services. Based on these results, a list of barriers was presented in both the Survivor and Providers Surveys. Respondents were asked to check all the issues that presented barriers to their use of services, or in the case of providers, to the individuals with TBI and family members with whom they had worked.

The barriers to service that emerged through this process echo service gaps identified by providers, advocates, individuals with TBI, and family members. The top barriers identified by all sources of information were:

- Lack of knowledge about TBI among providers as well as individuals with TBI and families
- Lack of information or inaccurate information about TBI services
- Ineligibility for services and financial support due to age, severity of injury, pre-existing injury, and/or income
- Lack of funding and services for long-term support

Results from the surveys are shown below in Table 9.

Table 9: Survey Respondents' Report of Important Barriers to Finding & Using Services

Barriers to finding and using services	Percent of Providers	Percent of Survivors	Percent of all respondents
Providers lack knowledge about brain injury	41%	27%	34%
Services do/did not exist	37%	25%	31%
No available information about services	27%	30%	29%
Lack of lifelong services	36%	23%	29%
Denial or attitude of survivor	31%	17%	24%
Not eligible for Medicaid	30%	15%	22%
Absence of an advocate	26%	16%	21%
No transportation to get to services	21%	15%	18%
Didn't know there was a TBI	26%	5%	12%

Focus group participants identified two barriers that did not emerge from the other sources: case management limited to specific systems or facilities and less available to

individuals with mild or moderate injuries; and, difficulty with transitions, including lack of information, support, and consistent case management at times of transition.

How do we know if the service system is meeting the needs of individuals with TBI and their families?

Questions about outcome measures were primarily addressed by key informants. Focus group participants concurred with key informants by talking about similar issues in their own lives. The question was too complex to present in the context of a survey, so was not addressed by survey respondents.

The primary measure of successfully meeting the needs of individuals with TBI and their families was identified in various ways as satisfaction with quality of life. That is, a successful service system would promote satisfactory quality of life for individuals with TBI and their families. In particular, quality of life indicators would include:

- Meaningful occupation or daily activities
- Successful employment
- Successful transition from school to adult life
- Social opportunities and community participation
- Time and opportunities for enjoyment, laughter, and fun

In addition to a satisfactory quality of life, key informants noted that a successful service system would promote community integration for individuals with TBI. This would include:

- Independent living in a community setting to the extent possible for each individual with TBI
- Safety for everyone involved
- Services available in Vermont

In addition to these measures of quality of life and community integration, a successful service system would support and promote continued progress in recovery for all individuals with TBI.

VI. CONCLUSIONS

Vermont currently does not have a comprehensive system of services for individuals with TBI and their families. In general, the more severe the injury and the higher the level of need, the more likely an individual with TBI is to receive comprehensive services and supports. In particular, the system lacks services for people who have suffered mild to moderate TBI. This is closely tied to the fact that individuals with mild to moderate TBI frequently are unidentified. Lack of identification is closely tied to lack of awareness about TBI among the general public, professionals, educators and service providers. Inadequate data sources to track incidence and prevalence of mild to moderate TBI also contributes to this problem.

For individuals with TBI who meet eligibility criteria, services provided under the TBI Waiver are regarded as comprehensive, appropriate and of high quality. But even the TBI Waiver is not designed to meet the long-term needs of many individuals with TBI and their families. For individuals who are not TBI Waiver-eligible, it is difficult to access comprehensive services, even for those with private insurance coverage or personal financial resources. For these individuals, it is a patchwork of services and supports with gaps and varying eligibility requirements.

Information drawn from all three information sources – the focus groups, key informant interviews and surveys – pointed to the following as the most important elements in a system of services for TBI survivors and their families:

- Employment, including long-term employment supports (work was reported by survivors as the area of life changed most by TBI)
- Family supports and respite
- Home-based services (life skills aides, personal care attendants, home health aides, nursing care)
- Information and referral (accurate, consistent information to assist with accessing appropriate services)
- Case management or service coordination (consistent, ongoing case management across service providers and treatment settings)
- TBI Waiver or Waiver-type services (including case management, funds for TBI services and supports)
- Trained and knowledgeable health care, mental health, and direct care providers

- Long-term services and supports (including rehabilitation therapies, case management, home based services without durational limits, ongoing employment supports)
- Transportation

Additional elements identified by the needs assessment as important to a system of services for individuals with TBI and their families are:

- Flexible systems and funding (including eligibility barriers and insurance limits)
- Financial assistance for daily living and services
- Social opportunities, support groups, and counseling
- Public education and awareness, including prevention
- Rehabilitation therapies

Barriers to services and supports identified by the needs assessment mirror the gaps in the current service delivery system. They include:

- Lack of knowledge about TBI among providers, as well as individuals with TBI and their families
- Lack of information or inaccurate information about TBI services
- Ineligibility for services and financial support due to age, severity of injury, pre-existing injury, and/or income
- Lack of funding and services for long-term support (home and community based and employment)

Vermont has a number of model programs to address the needs of individuals with TBI and their families. However, information gathered from all sources in the needs and resource assessment, as well as from TBI Program staff, points to the need to create a comprehensive system of TBI services and supports for Vermonters with TBI and their families.

APPENDIX A

TBI Needs and Resources Assessment

Summary of Key Informant Interview Findings

Methodology

As part of the TBI Needs Assessment, a series of individual interviews was conducted to gather qualitative data from professionals representing a variety of health care, service provider, and advocacy perspectives. Twenty-four (24) key informants were interviewed, primarily by telephone, using a structured set of questions. The questions and responses are summarized below.

Findings

1. How do individuals with TBI get into the system of support services?

The only nexus for TBI service that emerged from the interviews was the TBI Waiver Program, which serves only people with severe TBI. The conclusion may be drawn that there is no actual system of TBI services in Vermont, as several informants stated. Various paths of entry, or gateways, to receiving services emerged:

- Hospitals and rehabilitation facilities play key roles in providing services and referring patients to services upon discharge.
- Long-term care system, e.g., Medicaid Home and Community Based Waiver, nursing homes, residential care, home health agencies
- Attorneys and other advocates
- Psychological services, including evaluation
- Schools, including school nurses, evaluation within the educational setting, and coaches
- Employment services, including Vocational Rehabilitation and Workers Compensation

2. Are there ways to find people (both adults and children) who have received a brain injury but have not been identified as individuals with TBI (e.g., people who are undiagnosed or misdiagnosed)?

Two suggestions recurred with frequency:

- Widespread education about brain injury is necessary to increase identification of persons with brain injury. Suggestions ranged from a broad-based public awareness campaign (e.g., understanding the connection between concussions and brain injury) to educational efforts targeted at specific, critical audiences, such as health care providers, mental health providers, special educators, school nurses and coaches, elder services, and correctional providers.
- Most agencies conduct some kind of intake assessment for new patients or program participants. Develop a uniform, clear brain trauma question to be included in intake assessment questionnaires to identify people who are currently being missed

3. Do you have suggestions about where we might find information on the prevalence and/or incidence of TBI in Vermont?

Key informants offered suggestions about a variety of potential sources of data about the incidence and prevalence of TBI in Vermont. However, most of these sources do not gather TBI data in a consistent or systematic way. Lacking a TBI registry or unique identifier system, some individuals would invariably be counted and reported by more than one source.

4. What are the sources of funding for TBI services, both public and private?

Informants identified a variety of funding sources for TBI services in Vermont:

Adults: TBI Waiver, Medicaid, Medicare, commercial health insurance, Workers Compensation, Vocational Rehabilitation, long-term care services through the Dept. of Aging and Disabilities (Home and Community Based Waiver, Enhanced Residential Care Waiver, personal care services, homemaker services)

Children/Youth: Medicaid, Special Education, Family/Infant/Toddler Project, Children with Special Health Needs

Additional sources: Vermont Association of the Blind and Visually Impaired, Vermont Center for Independent Living, Enable Loan Fund, Veterans Administration, Vermont Adaptive Equipment program, disability income, legal settlements, personal funds (including credit cards, proceeds from selling personal resources, family loans and gifts)

5. What specific services do you believe are needed for individuals with TBI, including those of different ages, severity of injury, and cultural backgrounds?

Several types of services were repeatedly cited as necessary for all individuals with TBI:

- Accurate assessment, evaluation, and diagnosis to ensure appropriate treatment (and treatment plans) and referrals, including training to accomplish this
- Case management and service coordination
- Quality work force trained to work one-to-one with individuals with TBI (e.g., life skills aides, home health direct care workers, nursing home staff), including training on behavioral issues
- Public education to increase awareness and understanding of TBI
- Information and referral services
- Support and respite for families/caregivers
- Transportation
- Expansion of eligibility criteria for TBI Waiver

Additional services were cited for specific populations:

Adults: long-term employment supports, appropriate programming for younger adults in nursing homes

Children/youth: long-term supports during/after transition to adult life, in-state rehabilitation facility with expertise in serving children, improved education services and accommodations, peer support groups, counseling for children and their families

Elders: medical advocacy to support family caregivers, education to prevent falls

Culturally diverse populations: access to health care, language interpreters, cultural competence training for health care and service providers, life skills aides with same background as the individual with TBI, medical and social advocacy

6. To what extent are these services available in Vermont? What do you see as critical gaps in services?

Overall, informants reported that services provided to individuals with severe TBI under the TBI Waiver are excellent, although often Waiver services are too short in duration. However, for those not eligible for the TBI Waiver, even when a source of payment is available, access to services and the quality of those services is extremely limited. In general, except for those currently on the TBI Waiver, service needs are not being met. Lack of access to good assessment, case management, trained life skills aides, and information about TBI and services were repeatedly cited as gaps.

The following critical gaps in services affecting all groups were noted:

- Services for individuals with mild-moderate TBI (family members carry the burden as a result)
- Appropriately trained and compensated staff in all settings
- Access to appropriate assessment, evaluation, and consultation, in particular neuropsychologists
- Transportation
- Access to information about TBI and TBI services
- Services and supports for families
- Statewide access to high quality immediate care statewide (e.g., brain cooling, pressure measures)

Numerous additional service gaps were noted for adults, children/youth, elders, and culturally diverse populations.

7. Describe barriers you see for individuals finding, getting and using TBI services.

The major barrier to finding, getting and using TBI services identified by informants was ineligibility for the TBI Waiver. One informant described an all or nothing situation where “you are either in the system or out of it.” Additional barriers can be broken down into several categories:

Eligibility barriers: ineligibility for TBI Waiver and general Medicaid, delays in disability determinations for SSI and Medicaid, services tied to eligibility for specific programs, two-year waiting period for Medicare

Funding barriers: lack of funding for long-term supports, lack of flexibility in how funding can be used, limits on type/duration of services funded by private insurance and Medicare

Training and public education barriers: lack of public awareness about TBI, lack of training for health care professionals and other service providers, lack of appropriately trained one-to-one staff, lack of cultural competence training

Information and advocacy barriers: lack of access to information and referral services for TBI, lack of access to knowledgeable advocates, lack of family support system

Personal barriers: stigma of TBI, lack of insight of some individuals with TBI about their limitations and need for services, denial, substance abuse issues, behavioral issues

Other barriers: lack of transportation, rural nature of Vermont, physical inaccessibility of programs and services, lack of interagency collaboration, limited contact with doctors in nursing homes, lack of appropriate housing options

8. How do we know if the service system is meeting the needs of individuals with TBI and their families? What outcomes would you expect to see if the system were meeting needs?

Individual satisfaction with quality of life (using a variety of indicators such as independent living to the extent possible, continued progress in recovery, successful transitions, meaningful occupation or daily activity) was suggested by many informants as the best way to know whether individuals' needs are being met. Others spoke to the system of services rather than to outcomes for individuals, and looked to systemic outcomes such as adequate funding for TBI services, easy access to a full array of services, increased number of identified individuals with TBI (indicating more understanding of TBI and potential use of services), and minimized number of individuals with TBI in nursing homes and correctional facilities.

9. Based on your experience, what is the most critical issue for individuals with TBI?

The most critical issues for individuals with TBI closely tracked the service needs, gaps and barriers cited in response to earlier questions. Access to appropriate evaluations, good information, case management, family support, and the TBI Waiver topped the list of critical issues identified by informants.

APPENDIX B

TBI Needs and Resources Assessment

Summary of Focus Group Findings

Methodology

A focus group study was conducted in February 2003 to gather qualitative data from individuals with TBI and family members as part of the TBI Needs Assessment. The study targeted three populations: children and youth up to age 25 with injury occurring prior to age 18, adults ages 26 to 59, and elders ages 60 and older. Recruitment difficulties led to cancellation of the elders' group, and three individual telephone interviews were conducted in its place. The children and adult groups were held as planned.

In total, sixteen (16) individuals with TBI and family members participated in the focus groups and individual interviews. The gender of the individuals with TBI was almost equally divided¹⁰, and a mix of severity of injury ranging from mild (2) to moderate (2) and severe (12) was represented. Individuals' areas of residence included rural, semi-urban, and urban.¹¹

Participants for the focus groups and individual interviews were recruited by a variety of state and non-profit agencies who screened prospective participants for criteria relevant to their specific group. Participants were offered a \$50 stipend as an incentive to participate, as well as reimbursement for mileage and personal care attendants.

Findings

Primary themes

Five primary needs and gaps in services rose to the top in all of the discussions:

- Case management
- Information and referral
- TBI Waiver and Waiver-type services
- Advocates
- Transitions

¹⁰ Demographic characteristics represent the characteristics of the individual with the TBI, not the family members.

¹¹ Semi-urban areas include Barre, Montpelier, and Rutland. Residents of Chittenden County, the state's only standard Metropolitan Statistical Area, are considered urban.

Case management: Case management was the most frequently identified need. It was described as very helpful by those who had received it, and the lack of ongoing, consistent case management was identified as a major barrier to receiving needed services and to achieving a good quality of life. The case management that is currently available was characterized as typically limited to the specific system or facility in which the case manager works (e.g., a hospital, nursing home, insurance company, rehabilitation facility, or school). As a TBI survivor moves from one system or facility to the next, their case manager changes as well. As survivors make progress in their recovery, they often “graduate” from the programs that have provided case management, leaving them without assistance on an ongoing basis. For survivors of mild and moderate brain injuries, case management may be unavailable at any time post-injury. The case management desired by focus group participants goes well beyond medical case management and includes comprehensive case management that can help to identify services and navigate the service delivery system, as well as assist in the school setting, with financial matters, work-related issues, obtaining needed accommodations, and other matters of daily life. Case managers also serve a critical role in coordinating a sometimes bewildering array of health and social services in a highly fragmented service delivery system. Case management services may be needed many years post-injury and even life-long.

Information and referral: Participants were hungry for information, and noted that their information needs change over time, from information about brain injury and what to expect at the time of injury, to information about services and resources as they progress in their recovery. They characterized the information that is currently available to them as limited, superficial, and not specific enough. They also spoke of the profound negative impact of receiving misinformation about services, eligibility, and legal and financial issues. The Internet was the most frequently cited source of information, although many said that they do not have adequate time to do the research or make sense of the information they find there.

TBI Waiver and Waiver-type services: Participants indicated a strong desire for the types of services that are provided by the TBI Waiver Program, such as case management, well trained aides, crisis support, counseling, and a team approach. Those who were ineligible for the TBI Waiver due to age, severity, pre-existing injury, or income expressed their desire to receive those services. The unavailability of those services to individuals with mild and moderate brain injuries was noted as a particular issue. Waiver-type services are often needed on an ongoing basis, not just during rehabilitation, and several participants noted that the length of time they were allowed to stay on the TBI Waiver was insufficient to meet their needs.

Advocates: The need for advocates was a common theme, and their assistance is needed in all kinds of settings and with many issues—workplace accommodations, at school, dealing with insurances, eligibility and benefits, with assistive technology, getting needed services for health care providers, and more. Advocates can also model effective practices that individuals with TBI and family members can use in advocating for themselves.

Transitions are difficult: Participants described a variety of transitions, all of which caused problems. For individuals with TBI, every change to a new environment may present a challenge. These include moves from one institutional setting to the next, from out-of-state facilities back to Vermont, from rehab to nursing home, residential care or home, and from the TBI Waiver to other services. Younger people and their families experienced additional challenges in making transitions from a structured school environment to an unstructured summer environment, and from high school to college without aides and other supports. Participants spoke of the impact of lack of information, support, and consistent case management during these times of transition, when they need it most.

Secondary themes

There were a number of additional recurrent themes across the three target groups:

- Denial by individuals with TBI and family
- Importance of support groups for individuals with TBI, family members, youthful siblings
- Need for family support
- Provider attitudes and need for training
- Transportation
- Respite for families
- Employment
- Legal assistance
- Source of payment drives benefits
- Housing
- Public education about brain injury, including prevention
- No system of care/lack of interagency coordination
- Importance of optimism and patience

Additional issues raised

Participants identified a range of additional needs. While these topics did not recur with the frequency of the primary and secondary themes, they were identified as critical issues by the individuals who raised them.

- Thorough neuropsychological assessment followed by a treatment plan
- Training for and a reliable supply of personal assistance workers
- Technical assistance, repair and problem-solving with assistive technology
- Lack of daytime and community based activities for adult individuals with TBI, and support to participate in activities
- Lack of consistency in home care providers and personal care assistants
- Inadequate long-term care options for individuals with TBI who need lifelong care; nursing home care is custodial rather than restorative

- Every individual with a brain injury is different, yet systems lack flexibility to respond to individual needs
- No mechanism exists for recipients of services to provide evaluation or feedback about the services they receive under the TBI Waiver

APPENDIX C

TBI Needs and Resources Assessment

Summary of Survivor and Provider Survey Results

July 8, 2003

Methodology

The TBI Needs and Resources Assessment involved three methods to gather information about individuals with TBI and their families. First, key informant interviews were conducted with 24 providers and advocates. Second, focus groups were conducted with individuals with TBI and family members representing children, adults, and elders. Results from both of these efforts were used to construct Provider and Survivor Surveys, using the Health Resources and Services Administration's (HRSA) *Traumatic Brain Injury Needs and Resources Assessment Tool* as a starting point. The surveys were designed to determine how widely shared were issues raised by key informants and focus group participants.

Surveys were distributed to 1,419 individuals with TBI and 1,125 providers using a variety of mailing lists and professional organizations. The goal was to ensure that surveys reached a wide range of individuals, particularly individuals with mild, moderate, and severe TBI. Respondents returned completed surveys in self-addressed postage-paid envelopes directly to the TBI Program at the Department of Aging and Disabilities (DAD).

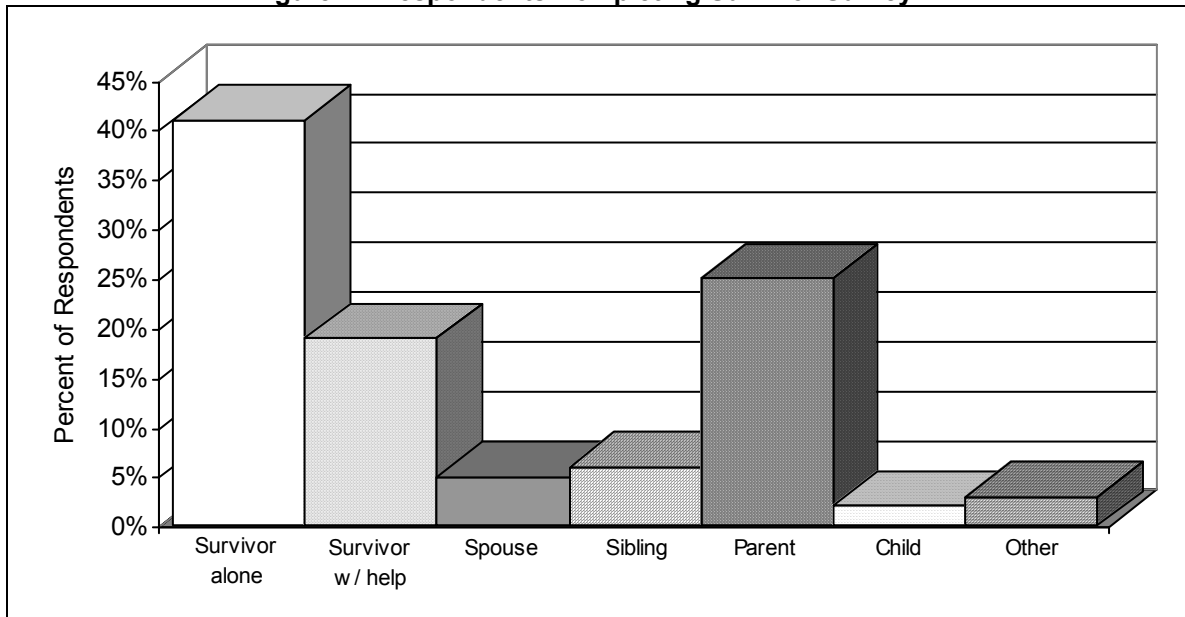
Survey Respondents

Of the 1,419 Survivor Surveys distributed, 190 (13.4%) were returned. Providers returned 183 (16.3%) of the 1,125 surveys distributed.

Individual with TBI (or representative) respondents

About 40% of the surveys were completed by individuals with TBI on their own (see Figure 1); another 20% of the surveys were completed by individuals with TBI with assistance from someone else. Parents of individuals with TBI completed about one-quarter of the surveys. Interestingly, about as many spouses as siblings completed the survey.

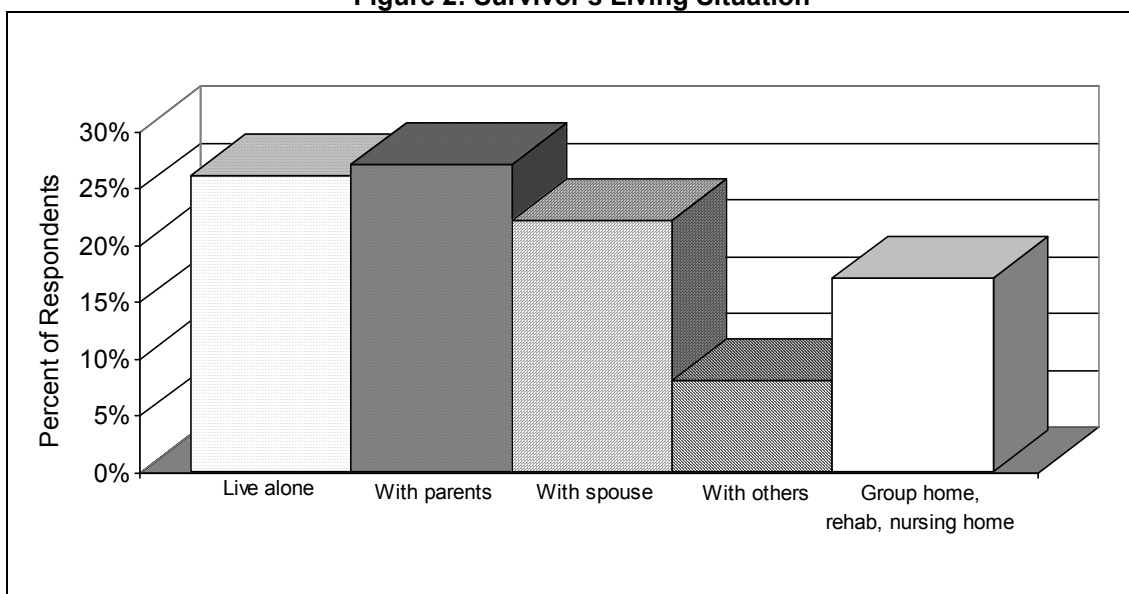
Figure 1: Respondents Completing Survivor Survey



Although not all Survivor Survey respondents were individuals with TBI themselves (indeed about 40% were not individuals with TBI), the remaining discussion will refer to respondents as “individuals with TBI.” The survey respondents were asked to answer the questions as if they were the individual with TBI.

Most individuals with TBI in the survey lived on their own, with their parents, or with their spouse (see Figure 2). Of the 16% of individuals who lived in institutional or group setting, 7% lived in group homes, 5% lived in rehabilitation facilities and 4% lived in nursing homes. Of the 15 (8%) individuals with TBI living with others, 4% lived with roommates, 2% with other family members, and 3% with caregivers or guardians.

Figure 2: Survivor's Living Situation



On average, individuals with TBI sustained their brain injury at 27.5 years of age (standard deviation = 15.3); and at the time of the survey individuals with TBI were on average 39.6 years of age (standard deviation = 14.7).

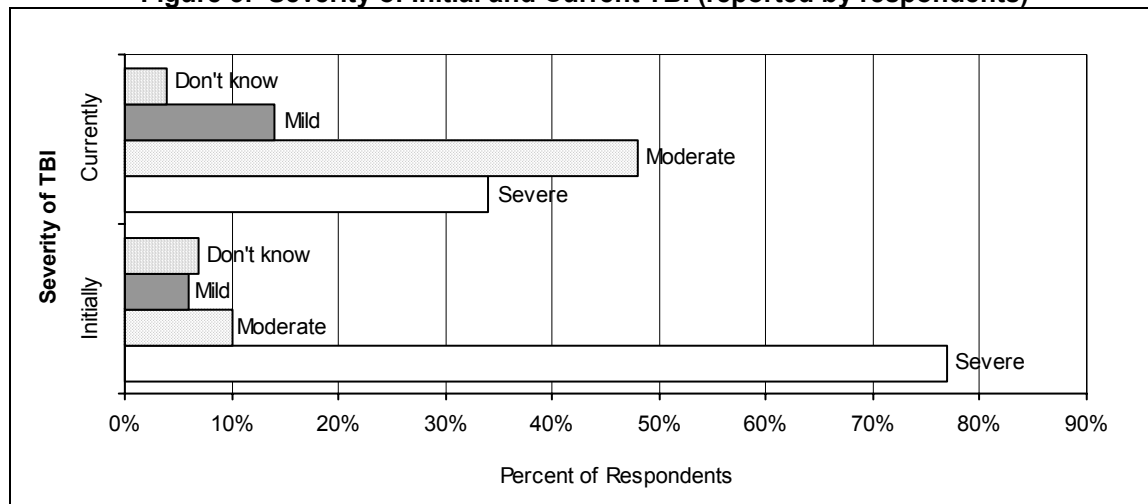
As shown in Table 1, the average (or mean) age at injury ranged from 11 to 40, depending on the type of injury. Consistent with national data, the most frequent cause of brain injury among this sample was car accidents. Medical conditions included brain tumors and anoxia. Of the 7 sports accidents, none involved school-age sports, rather these were accidents involving horseback riding, skiing, mountaineering, and jogging.

Table 1: Cause of and Age at Injury for Survivor Survey Respondents

Cause of injury	Frequency	Percent	Mean Age at Injury (standard deviation)
Car accident	83	44%	24.2 (13.0)
Medical condition	20	11%	26.4 (18.6)
Stroke at young age	19	10%	40.0 (14.5)
Pedestrian accident	15	8%	30.4 (19.0)
Assault or abuse	11	6%	21.1 (18.1)
Bicycle accident	10	5%	29.0 (10.7)
Fall(s)	8	4%	24.4 (15.4)
Sport activity	7	4%	31.3 (16.5)
Near drowning	2	1%	11.0 (7.1)
Firearms	3	2%	38.3 (7.2)
Other	10	5%	33.9 (9.7)
TOTAL	188	100%	27.5 (15.4)

Respondents were asked to rank the severity of the brain injury when it initially occurred, and then to rank how the injury “affects you today.” As shown in Figure 3, the vast majority of surveys were completed by individuals (or their representatives) who initially had a severe brain injury. However, currently, only about a third of respondents felt the TBI continued to be severe.

Figure 3: Severity of Initial and Current TBI (reported by respondents)



Provider Respondents

Surveys were returned by providers working in a wide range of organizations. As shown in Table 2, nearly one quarter of the respondents worked in agencies that provided rehabilitation services, and 37% of these agencies provided rehab services alone. Most of the home health agencies (80%) did not provide any other service, while nearly all of the those agencies providing information and referral, as well as substance abuse services, provided other services as well.

Table 2: Services provided by survey respondents' agencies

Type of Services Agency Provides	Percent of Sample
Medical	15%
Rehabilitation	23%
Home Health	11%
Mental health/developmental services	14%
Employment/vocational	10%
Educational	14%
Information & referral	10%
Advocacy	12%
Substance Abuse	2%
Long term residential	10%

There was a similarly broad representation of agencies by type of service setting (see Table 3). Most of the in-patient and outpatient facilities also provided services in other settings, while all of the schools responding were schools only.

Table 3: Settings for services provided by survey respondents' agencies

Settings in which services are provided	Percent of Sample
In-patient	26%
Out-patient	25%
Day treatment	8%
Home-based care	25%
Community-based care	35%
Residential program	14%
School	8%
Office setting	6%

Respondents themselves represented direct care providers (53%), administrators (39%), and advocates (15%). Several respondents held multiple roles.

Survivor Survey Results

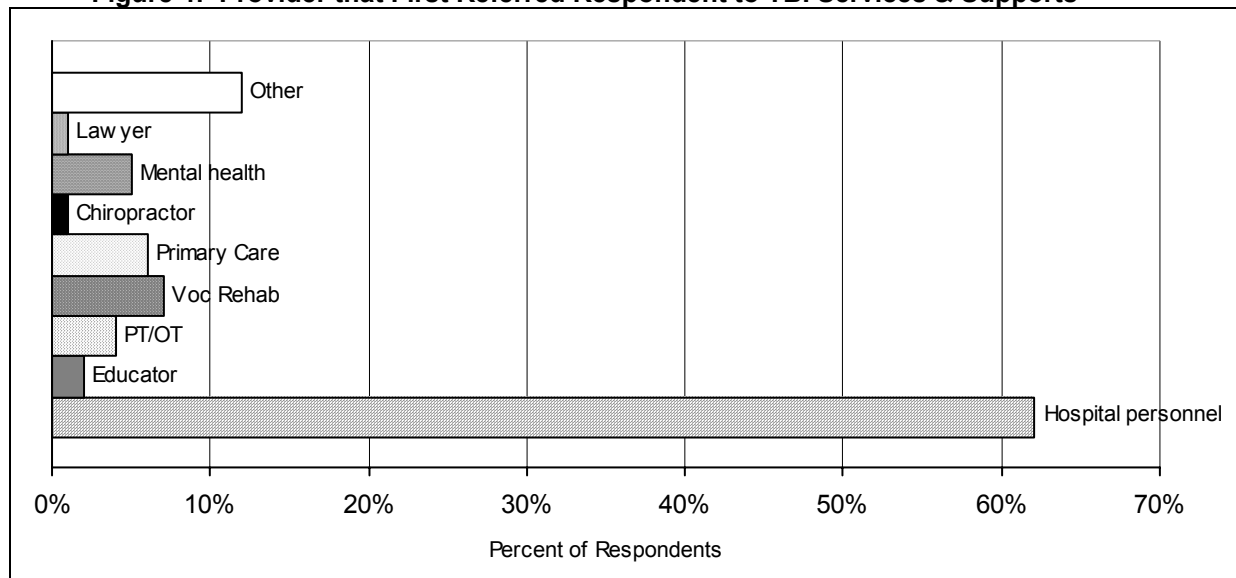
Entry into the system of support services for brain injury

Given that the majority of respondents had severe brain injuries, it is not surprising that most individuals with TBI (78%) learned that they had a brain injury through hospital personnel. Of respondents with an initially severe injury, 83% learned of their injury through hospital personnel. Even 63% of respondents with moderate injuries learned

through hospital personnel, while 21% learned of their injury through a family doctor or pediatrician. Of the few cases of initially mild injuries, 55% of respondents learned of the TBI through hospital staff, while 27% learned through pediatricians or family doctors.

Not surprisingly, then, when asked what type of provider first referred them to services for TBI, the majority identified hospital personnel (see Figure 4). Half of the “other” referral sources were either “no one” or “I don’t remember.” The remaining “other” sources were either self referral or referral by a family member/friend.

Figure 4: Provider that First Referred Respondent to TBI Services & Supports



Service Needs & Gaps

Several types of questions were used to explore issues that impact on respondents’ needs for services. The first set of questions addressed the impact of TBI on the daily life of individuals with TBI.

One survey question asked respondents to identify areas in their lives that had changed as a result of their brain injury. Table 4 presents the results in terms of initial and current level of TBI severity. Overall, 82% of all individuals with TBI said that their brain injury affected their work. While 85% of those with initially severe and 82% of those with initially mild injuries said work was affected, only 4% of those with initially moderate injuries said work was affected. However, 86% of those with currently moderate injuries felt the impact of their injuries on work.

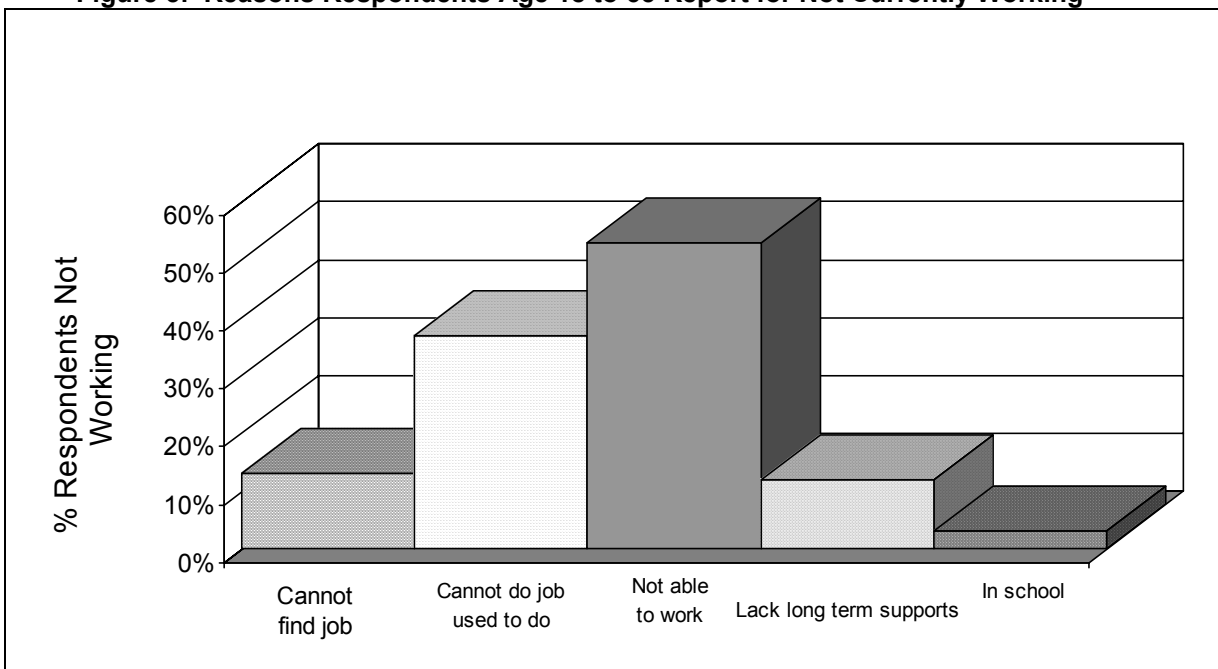
The other areas that were consistently and significantly impacted by TBI were “friendships and social relationships,” and “state of mind or psychological outlook.”

Table 4: Respondents' report of areas of life changed by brain injury

Area of life changed by injury		Severe	Moderate	Mild	All Survivors
<u>Work:</u>	Initial	85%	4%	82%	82%
	Current	85%	86%	65%	
<u>Friendships:</u>	Initial	80%	79%	73%	76%
	Current	85%	79%	65%	
<u>State of mind/ Psychological Outlook:</u>	Initial	78%	68%	82%	76%
	Current	89%	75%	62%	
<u>Health:</u>	Initial	65%	47%	91%	62%
	Current	82%	63%	19%	
<u>Marriage:</u>	Initial	58%	63%	64%	58%
	Current	68%	56%	46%	
<u>Living situation:</u>	Initial	61%	42%	27%	54%
	Current	81%	48%	19%	

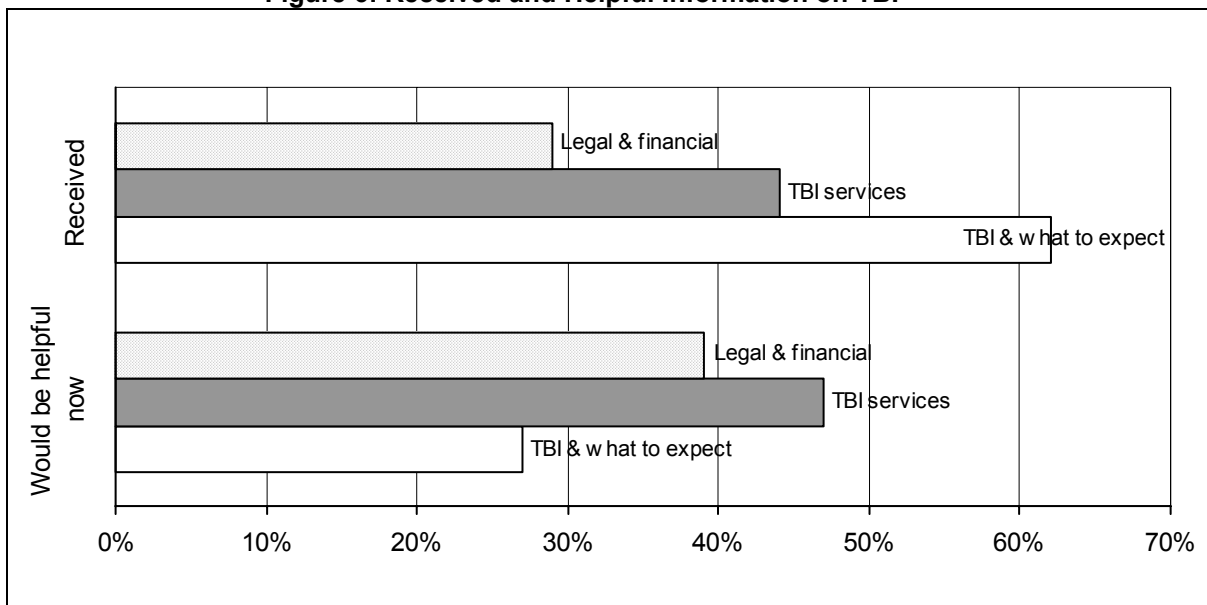
Two thirds (66%) of the respondents were currently not working. Of those with an initially severe brain injury, 70% were not working as compared to 40% of those with an initially moderate brain injury. However, 63% of those with an initially mild injury were not working. Looking at present severity, about 75% of those with currently severe and moderate injuries were not working, while 35% of those with currently mild injuries were not working.

When asked why they are not currently working, the majority of respondents aged 18 to 65 said that they were not able to work (see Figure 5). Another third of respondents said that they “cannot do the job I used to do.” Only 10% of these respondents identified the reason for not working as “lack of long-term work supports or accommodations.”

Figure 5: Reasons Respondents Age 18 to 65 Report for Not Currently Working

Focus group participants had sounded a very strong note for information of various sorts. The survey asked respondents whether they had “ever received information” about three topic areas: legal and financial matters; services for brain injury; and “information about what brain injury is and what to expect.” The next survey question asked if any of these types of information “would be helpful to you now.” As shown in Figure 6, the majority of respondents had received information on TBI; still, one third said this type of information would be helpful to them now. Less than half of the respondents had ever received information on TBI services, and nearly half would find such information helpful at present. Few respondents had received legal and financial information, and more than a third would find such information helpful now.

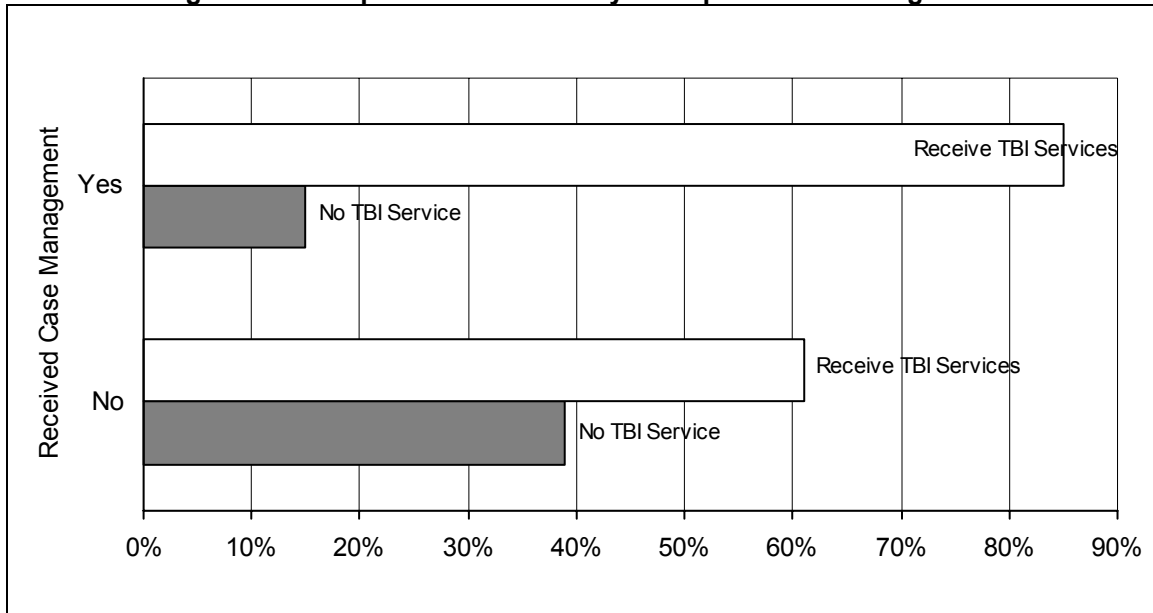
Figure 6: Received and Helpful Information on TBI



Survey respondents were asked if they receive services for brain injury. Nearly three-quarters of respondents, regardless of their initial level of TBI severity, reported that they had received services for their brain injury. Focus group participants and key informants had all stressed the importance of case management or service coordination to receiving needed services.

Survey respondents were also asked if they received case management services. Overall, 61% of respondents said they received case management. As shown in Figure 7, most of the respondents who said “yes” they received case management also said that they received TBI services. However, nearly 40% of those respondents who said “no” they did not receive case management said they did not receive TBI services.

Figure 7: Receipt of TBI Services by Receipt of Case Management



When asked which source of funding individuals with TBI used to pay for needed services and supports, respondents most frequently identified Medicaid and their own personal funds (see Table 5). Medicare and private insurance were the other most frequent sources of funding for services.

Table 5: Respondents' report of sources for funding services

Sources of funding for services	Frequency	Percent
Medicaid*	102	54%
Personal funds	82	43%
Medicare	76	40%
Private insurance	64	34%
TBI Waiver	54	28%
Vocational Rehabilitation	44	23%
Personal loans from family/friends	35	18%
Special Education funds	16	8%
Department of Employment & Training	11	6%
Children with Special Health Needs	9	5%
Veteran's Administration	10	5%
Workers Compensation	7	4%
Family, Infant & Toddler	5	3%
Early Essential Education (EEE)	4	2%

* Note: Of the 102 respondents receiving Medicaid, 43 were also on the TBI Program.

Individuals with TBI were asked to list the “three most important services you get now or that you have received in the past.” This was an open-ended question, so respondents could list whatever services they felt most important. Individuals with TBI listed a wide range of services, with several clear themes emerging (see Table 6). Rehabilitation

therapies such as occupational therapy (OT), physical therapy (PT), and speech therapy were most frequently identified as important to individuals with TBI. Next in frequency was home-based care, including support and aid from Life Skills Aids (LSA) and Personal Care Attendants (PCA). Equally as important to respondents as home-based care was funding for services and financial support for daily living. Various types of assistance with job skills and training (such as Vocational Rehabilitation) were identified as next in importance.

Table 6: Services most frequently identified as most important by individuals with TBI

Services Identified as Most Important by Respondents	Frequency	Percent
Rehab. Therapies (OT, PT, speech)	43	23%
Home-based care (LSA, PCA, etc.)	31	16%
Sources of funding (insurance, SSI, etc.)	30	16%
Voc Rehab/job skills	25	13%
Case management/service coordination	16	8%
Assistance with school, education	13	7%
Transportation	8	4%
TBI Waiver Program	7	4%

Respondents were then asked to identify “the one most important service that is missing from the services that you get.” As shown in Table 7, help with employment was at the top of the list, closely followed by financial assistance. Several respondents identified social needs (“I have no one to talk to.”) and psychological support as missing. Transportation and service coordination also were mentioned.

Table 7: Services most frequently identified as missing by individuals with TBI

Services Identified as Most Important by Respondents	Frequency	Percent
Rehab. Therapies (OT, PT, speech)	43	23%
Home-based care (LSA, PCA, etc.)	31	16%
Sources of funding (insurance, SSI, etc.)	30	16%
Voc Rehab/job skills	25	13%
Case management/service coordination	16	8%
Assistance with school, education	13	7%
Transportation	8	4%
TBI Waiver Program	7	4%

Family members completing the survey were asked to identify the “one most important service that you need.” Many respondents provided multiple answers to this question. Overall, families most need support groups or help coping with their family members’ TBI (see Table 8). They also need respite care, as well as information about TBI and, to some degree, case management or help accessing services.

Table 8: Services important to family members of individuals with TBI

Most Important Service Need Identified by Family Members	Frequency
Support Groups/help coping	21
Respite Care	17
Information/education on TBI	10
Case management/help getting services	7

Barriers to Services

Key informants and focus group participants identified a number of barriers to individuals with TBI and their families finding and using services. A list of these barriers was presented in both surveys. Individuals with TBI were asked to check all factors on the list that “stopped you from finding or using needed services.” As shown in Table 9, the most frequently identified barriers to accessing services were lack of information on how to find services and lack of TBI knowledge among providers. There were some differences in barriers across the initial level of TBI severity; however, none of these were statistically significant differences.

Table 9: Survivor Survey respondents report of barriers to services by initial severity of TBI

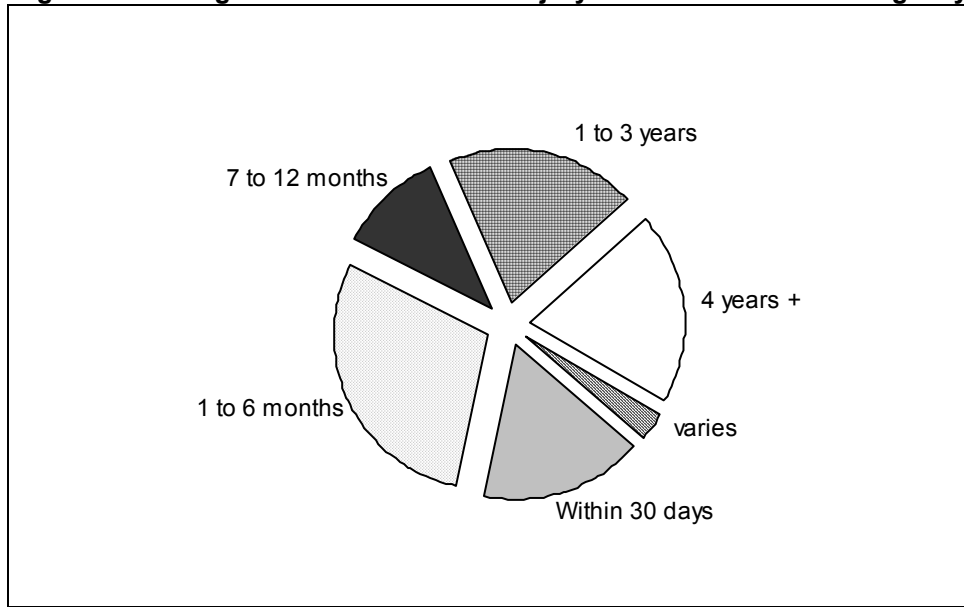
Barriers to finding or using services	Initial severity of brain injury						Total	
	Severe		Moderate		Mild			
	Frequency	Percent	Frequency	Percent	Frequency	Percent	Frequency	Percent
Couldn't find info on services	43	31%	7	37%	6	55%	57	31%
Providers lack TBI knowledge	36	26%	6	32%	7	64%	52	29%
Services do not exist	40	29%	4	21%	2	18%	46	25%
Lack of lifelong services	36	26%	3	16%	1	9%	42	23%
Provider negative attitudes	27	19%	3	16%	5	45%	38	21%
Survivor attitude or denial	24	17%	5	26%	1	9%	33	18%
No one to advocate	20	14%	2	11%	7	64%	29	16%
No transportation	23	17%	2	11%	3	27%	28	15%
Not eligible for Medicaid	14	10%	5	26%	7	64%	28	15%
Did not know had brain injury	2	1%	2	11%	1	9%	9	5%

Provider Survey Results

Entry into the system of services for brain injury

One survey question for providers asked the average amount of time following brain injury that people are “typically referred to your agency for services.” As shown in Figure 8, about 17% of respondents said people were referred to their agency for services within 30 days of the injury. Another 20% received referrals four years or more after the injury. Regardless of the type of services agencies provided, referrals were widely distributed across time since injury.

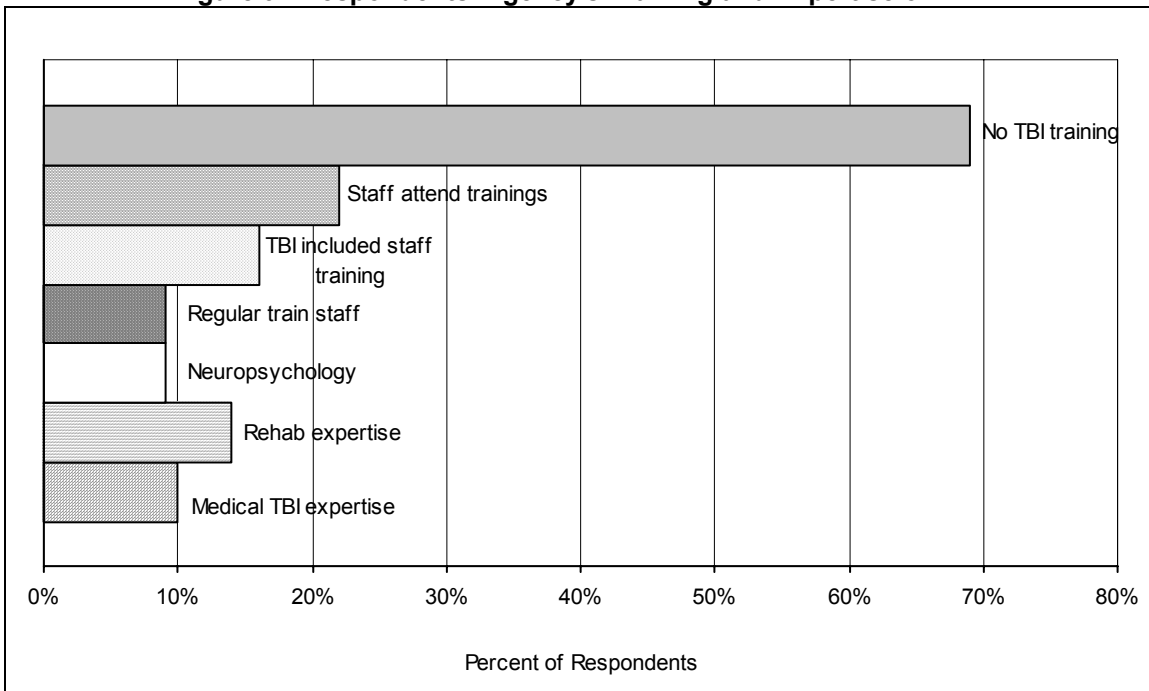
Figure 8: Average amount of time after injury clients are referred to agency



Service Needs and Gaps

Key informants and focus group participants identified well-trained staff with TBI expertise as critical to services. Providers were asked about training and expertise in two ways. First, they were asked about training or expertise their agency staff either bring to or receive through the agency. The vast majority of agencies represented by survey respondents did not have TBI training for staff or staff with TBI expertise (see Figure 9).

Figure 9: Respondents' Agency's Training and Expertise on TBI



Providers were then asked to identify the types of specialized training on brain injury they had personally received. As shown in Figure 10, nearly half of the provider respondents had not had any specialized TBI training. About one-quarter of the “other” training involved attendance at the annual TBI Conference.

Figure 10: Providers' Report of TBI Training They Received

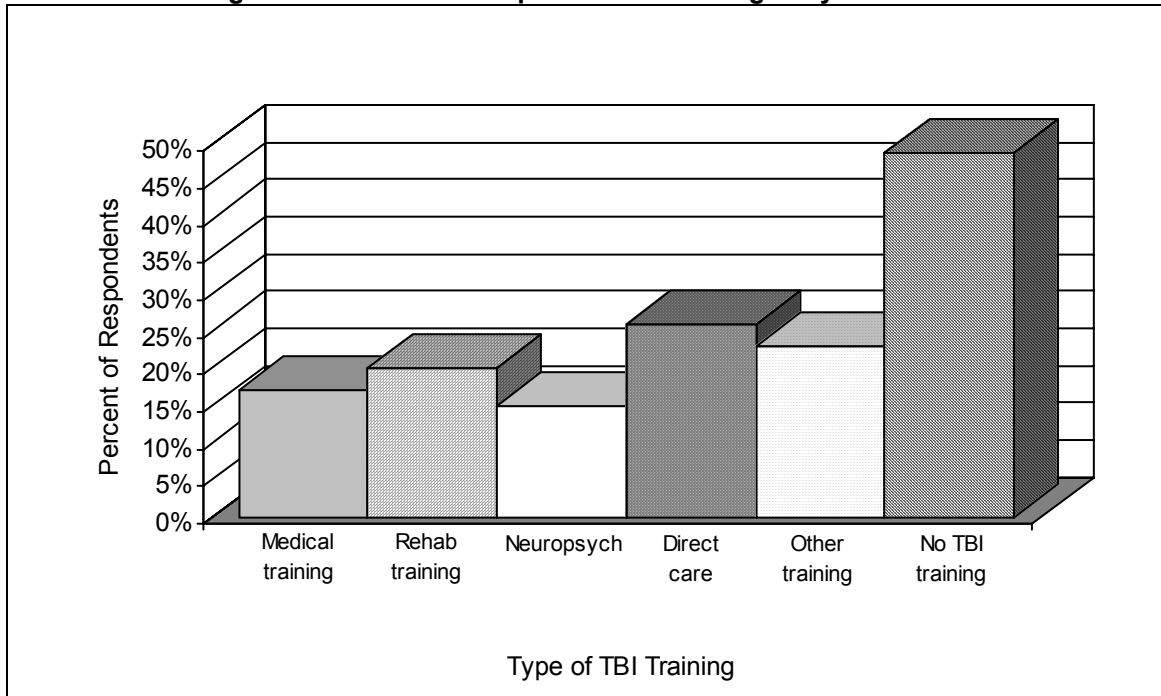


Table 10 shows that providers working in home health agencies were the most likely to have received TBI training, while those in agencies providing residential care and information and referral were least likely to have TBI training.

Table 10: Providers who received TBI training by their agency's services

Services Provided by Respondents' Agency	Number of Respondents Receiving TBI Training	Percent of Respondents whose Agency Provides these Services
Home Health	17	81%
Substance Abuse treatment	2	67%
Rehabilitation	28	65%
Mental health/Developmental Services	14	52%
Educational	13	52%
Advocacy	11	50%
Medical	13	48%
Employment/vocational	16	43%
Information & Referral	7	37%
Residential care	6	33%

Providers in community-based and residential settings were least likely to have received TBI training (see Table 11).

Table 11: Providers who received TBI Training by their Agency's Service Setting

Service Settings of Respondents' Agency	Number of Respondents Receiving TBI Training	Percent of Respondents whose Agency Provides these Services
Out-patient	30	65%
Home-based care	27	60%
School	8	57%
In-patient	27	56%
Office setting	6	55%
Residential program	10	40%
Day treatment	6	40%
Community based setting	25	39%

The Provider Survey asked respondents to list the “three most successful pieces of the service system for brain injury survivors and their families.” As shown in Table 12, the TBI Waiver Program and rehabilitation services were at the top of providers’ lists of successful elements in the service system.

Table 12: Providers’ List of Most Successful Elements of TBI Service System

Successful elements of TBI service system	Frequency	Percent
TBI Waiver Program and staff	31	17%
Rehabilitation services	25	14%
Psychological support, support groups (family & survivor)	18	10%
Trained, knowledgeable providers and specialists	17	9%
Family and survivor education	15	8%
Collaboration and cooperation among providers	14	8%
Case management and service coordination	14	8%
Evaluation, assessment and diagnosis of TBI	14	8%

Providers were then asked to identify “the three most significant brain-injury related services that are missing from the service system for individuals with TBI and their families.” Most frequently, providers said that long-term services and supports were missing. Next they identified limited program eligibility, limited availability of case management services, and lack of TBI training among professionals (see Table 13).

Table 13: Providers’ Most Frequently Identified Gaps in TBI Service System

Gaps in TBI Services	Frequency	Percent
Long-term services and support	39	21%
Limited program eligibility	28	15%
Limited availability of case management	23	13%
Lack of TBI training among professionals	20	11%
Limited funds for range of service needs	18	10%
Need for evaluation and assessment of TBI	10	6%

Barriers to Services

Providers, like individuals with TBI, were presented with a list of possible barriers to finding and using services. They were asked to check all the barriers they saw keeping individuals with TBI and family members from finding and/or using services. Respondents identified the lack of knowledge among providers as one of the top barriers to services (see Table 14). Overall, for all survey respondents, this ranked as the most frequent barrier. Next in line were the lack of services and the lack of lifelong services. Although there was not complete agreement between providers and individuals with TBI on barriers to services, the top three barriers were fairly similar between the two groups of respondents. Providers ranked lack of knowledge, lack of services, and lack of lifelong services as the top 3 barriers. Individuals with TBI ranked lack of information about services, lack of knowledge, and lack of services as the top 3 barriers.

**Table 14: Barriers to Finding & Using Services
as Reported by Providers & Individuals with TBI**

Barriers to finding and using services	Percent of Providers	Percent of Survivors	Percent of all respondents
Providers lack knowledge about brain injury	41%	27%	34%
Services do/did not exist	37%	25%	31%
No available information about services	27%	30%	29%
Lack of lifelong services	36%	23%	29%
Denial or attitude of survivor	31%	17%	24%
Not eligible for Medicaid	30%	15%	22%
Absence of an advocate	26%	16%	21%
No transportation to get to services	21%	15%	18%
Lack of appropriate services	41%	n/a	
Negative attitude of providers	n/a	20%	
Didn't know there was a TBI	26%	5%	12%

n/a: these questions were not asked of providers or survivors

Summary of Survey Findings

The Survivor and Provider Surveys were one tool in gathering information to address three specific areas of focus for the needs and resources assessment:

1. What are the paths of entry into services for individuals with TBI and their families?
2. What do individuals with TBI and their families need in terms of services and supports?
3. What are the barriers to finding and using TBI services and supports?

The individuals with TBI responding to the survey were predominantly people who had received severe brain injuries and entered the service system through hospitalization. Information about other paths of entry, therefore, was not available from this sample.

Survey respondents, though, did provide useful data on the needs of individuals with TBI and their families. Clearly, the needs of individuals with TBI are in the areas of work and social relationships. Their families need support and respite care. Looking at the data in combination, the following needs emerge from the points of view of individuals of TBI and providers:

Table 15: Needs Identified by Individuals with TBI and Providers

Needs identified by individuals with TBI (in order of frequency)	Needs identified by providers (in order of frequency)
Rehab therapies	Long term services & supports
Funding for service & financial support	TBI training for providers
Job skills, help finding & keeping a job	Case management
Home based care	Programs & eligibility serving range of needs across age, TBI cause, time since injury
Case management	Rehab therapies
Social opportunities	Diagnosis, evaluation, & assessment
Support groups, counseling	Support groups, counseling
Transportation	Funds to support range of services

Taken together, the data on barriers to services indicate that the following represent the most significant issues keeping individuals with TBI and their families from services:

- Providers' lack of TBI knowledge and training
- Lack of needed services
- Difficulty finding information about TBI services
- Lack of lifelong services